

**A Model of the Friendship Experiences of Young People Living with
Perinatally Acquired Human Immunodeficiency Virus**

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Abstract

The increasing survival of children diagnosed with Perinatally Acquired HIV (PAH) means this unprecedented population now face adolescence and young adulthood in the context of disease related stressors; most notably HIV stigma and decisions about sharing their HIV-positive status with others. Peer relationships become increasingly important during adolescence and young adulthood, and friends have been identified as a source of support during this time by young people living with other chronic health conditions. Emerging literature indicates there may be distinct features of friendship experiences for young people living with PAH. Existing research, however, is limited in quantity, does not separate PAH from other routes of HIV transmission or offers solely quantitative data regarding the friendships of the PAH population.

The aim of this Constructivist Grounded Theory (Charmaz, 2014) study was to explore, and create a model of, the experience of friendships for young people living with PAH. Nine young people aged 16-23 living with PAH were interviewed to answer research questions about the perceived effects for friendships of; having a mother who is HIV-positive, the friend's HIV status and decisions around HIV disclosure.

Eight theoretical codes were identified from analysis of interview data and are presented in a theoretical model of the friendship experiences of young people living with PAH: (1) Influence of paediatric disclosure experience on friendships, (2) Influence of mother's HIV status on friendship decisions, (3) Deciding whether or not

to share HIV status with friends, (4) Friendships with other people who do know HIV status, (5) Friendships with other people who do not know HIV status, (6) Friendships with other young people living with HIV, (7) Defining friendships and (8) Attitudes towards HIV. The results of this study are discussed with regard to future research and clinical work with the PAH population.

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Chapter 1: Introduction

Overview

This study investigates the friendship experiences of young people living with a diagnosis of perinatally acquired Human Immunodeficiency Virus (PAH). Medical advances have enabled PAH to be reconceptualised in recent years, from a terminal diagnosis to chronic one (Sherman, Bonanno, Wiener & Battles, 2000). The undoubted success of this progress is that young people born with PAH are now living much longer lives. The survival of this population is unprecedented though, and consequently there is an urgent need to examine psychosocial factors which are influential to their long-term wellbeing (Sherman et al., 2000).

This introduction will summarise the context of PAH, before outlining the unique combination of stressors encountered by young people living with PAH. Adolescence and young adulthood will be discussed, to understand the current developmental stage of the UK PAH population. Friendship experiences of the PAH population during adolescence and young adulthood are the specific focus of this research. Literature defining friendships and examining friendships in the context of living with a chronic health condition is therefore presented. Finally, research questions will be proposed for a qualitative investigation that facilitates the creation of a model of the friendship experiences of young people living with PAH.

Human Immunodeficiency Virus (HIV)

HIV is a chronic health condition which destroys the functioning of cells in the immune system and weakens the body's ability to fight infection. The virus inhabits CD4 cells designed to protect the body against infection and uses them to replicate itself. The process kills the CD4 cells and without treatment, prolonged damage from HIV leaves the number of CD4 cells so low (measured by the 'CD4 count') that people are vulnerable to life threatening infections and illnesses. The latest stage of HIV infection is Acquired Immune Deficiency Syndrome (AIDS) (World Health Organisation [WHO], 2014).

No cure currently exists for HIV, but there are effective 'antiretroviral' treatments (ARTs) which prevent the virus from replicating and halt progressive damage to the immune system. Adherence to ART supports effective management of the condition and enables people diagnosed as HIV-positive to live long lives without the infection developing in to AIDS (WHO, 2014). Blood tests that measure CD4 count and 'viral load' (the amount of HIV in a person's bloodstream) are used to monitor HIV. The CD4 count of a healthy adult is between 500 – 1200 cells/mm³ and a person living with HIV is at significant risk of serious illness if their CD4 count falls below 200 cells/mm³. The viral load is considered 'low' if it is under 10,000 IU/mL and the aim of ART is to achieve an 'undetectable' level of the virus in the bloodstream, usually indicated by a viral load of less than 40 IU/mL (National AIDS Manual, 2012).

There are an estimated 36.9 million people worldwide currently living with HIV (WHO, 2014). An estimated 25.8 million of those people live in sub-Saharan

Africa (Joint United Nations Programme on HIV/AIDS, 2015) and according to the most recent data available, there are an estimated 103,700 people living with HIV in the UK (Public Health England [PHE], 2015).

Routes of HIV Transmission

Transmission of HIV can occur behaviourally (behaviourally acquired HIV, BAH) via unprotected sex, exchange of bodily fluids with an HIV-positive individual or intravenous drug use. Alternatively, HIV can be transmitted perinatally (perinatally acquired HIV, PAH) from an HIV-positive mother to her child. This can happen in utero, during labour or postnatally as a result of breast feeding (Shetty, 2005).

Medical advances (ART during pregnancy, non-vaginal delivery, ART for the new-born baby) have resulted in a marked reduction in mother-to-child transmission of HIV. Transmission rates for PAH declined by an estimated 40% between 2009 and 2013 in low and middle income countries (WHO, 2014). Mother-to-child transmission rates have also declined in the UK, from approximately 20% in the 1990s (Duong, Ades, Gibb & Tookey, 1999) to a current rate of 5 HIV-positive infants per 1000 births to HIV-positive mothers (Townsend et al., 2014).

The PAH Population in the UK

A cohort of children born before developments in the treatment of HIV-positive pregnant women, or in countries without effective 'prevention of mother to child transmission programmes' (PMTCT), are now entering adulthood with a diagnosis of PAH (Foster et al., 2009). Their unparalleled survival presents an urgent

need to understand factors affecting the physical health and wellbeing of this population, as they transition through adolescence and young adulthood in the context of living with HIV (Mofeson & Cotton, 2013).

A cohort study of HIV-positive children living in the UK (Collaborative HIV Paediatric Study [CHIPS], 2015), had 979 participants in active follow up in 2014; nearly all of whom (93% of the cohort) had acquired the virus through mother-to-child-transmission. Of the 979 in the cohort, 53% were female, and 48% were born in the UK or Ireland. Data on ethnicity reported 78% of the cohort were Black African, 10% mixed ethnicity, 6% white and 1% each for black (other), Indian and other ethnicities (ethnicity unknown for remaining 3%). The median age of the population was 17 years old (interquartile range = 13.5 – 20.7 years).

Differences Between the BAH and PAH Populations

There are distinct differences between the BAH and PAH populations. Lifestyle differences include higher levels of alcohol and recreational drug use in the BAH population (Conner et al., 2013) and decreased likelihood of being sexually active in the PAH group (Bauermeister et al., 2009). People living with PAH are also at greater risk of cognitive deficits (Laughton, Cornell, Boivin & Van Rie, 2013) and may be exposed to more stressors such as long term hospital care (Bauermeister, Elkington, Brackis-Cott, Dolezal & Mellins, 2009) than the BAH population. The BAH population are older (PHE, 2015) than the PAH population. Unlike the BAH group, young people with PAH have also been exposed to HIV within their families (Hosek, Harper & Robinson, 2002), potentially including HIV-related bereavements

(Bauermeister et al., 2009). Despite these differences, the PAH population are frequently combined with the BAH population in existing research (Sohn & Hazra, 2013). Additional research focusing on the PAH population separately is necessary, to inform the care of this group.

Specific Considerations for the PAH Population

Young people living with PAH face a unique constellation of potential influences on their physical health and emotional wellbeing. Three of the most prominent factors; HIV stigma, HIV disclosure and the family context of PAH, will be discussed. Other factors which may be important to fully understanding the experience of the PAH population are also reviewed.

HIV Stigma. Living with a stigmatised and transmittable illness is central to the experience of the PAH population (Mellins & Malee, 2013). Goffman (1963) first identified stigma as a social process, in which particular characteristics get constructed as both socially devalued and indicative of negative qualities in people who possess them (Earnshaw & Chaudoir, 2009). Factors such as loss of status (Link & Phelan, 2014) and power differences (Aggleton & Parker, 2002) have been highlighted as ways in which wider social contexts can maintain stigma (Earnshaw & Chaudoir, 2009).

Earnshaw and Chaudoir's (2009) HIV Stigma Framework identifies 'being HIV-positive' as an example of a socially devalued characteristic. The authors propose that several stigma mechanisms impact people who do, and also people who do not,

have this characteristic. For those who are HIV-negative, the stigma mechanisms represent their efforts to separate themselves from people who are HIV-positive. These mechanisms are; holding negative emotions towards people living with HIV (prejudice), applying negative group based beliefs to individuals who are HIV-positive (stereotyping) and the behavioural expression of prejudices toward people who are HIV-positive (discrimination). For people who are HIV-positive, the stigma mechanisms represent their experience of possessing the socially devalued characteristic. These mechanisms are; direct experiences of prejudice and discrimination from other people in the community (enacted stigma), expecting to experience prejudice and discrimination in the future (anticipated stigma) and endorsing negative beliefs themselves about being HIV-positive (internalised stigma) (Earnshaw & Chaudoir, 2009).

The three mechanisms constituting the experience of people who are HIV-positive have potentially harmful consequences for the wellbeing of this group. Experiencing enacted stigma can result in psychological distress and a reduction in physical health for people living with HIV (Aggelton & Parker, 2002). Young people living with PAH may also encounter enacted stigma resulting from prejudice and stereotypical beliefs about the lifestyle of someone who is HIV-positive. People may assume these young people are using recreational drugs or engaging in other high risk behaviours (Kang, Mellins, Ng, Robinson & Abrams, 2008), which could result in discrimination. Encountering prejudice can also conflict with messages from the home environment, if young people living with PAH have been reassured by family that they were innocent in the acquisition of HIV (Kang et al., 2008). This could

result in confusion for the young person about how to perceive their HIV status¹. In addition, peers of young people living with PAH are at an age where they are exploring their own views and opinions about the world. Consequently, they may make discriminatory or stigmatising remarks about HIV without being aware of their friend's status (Wright, Naar-King, La, Templin & Frey, 2007) which heightens anticipated stigma for the young person living with PAH (Wright et al., 2007). Anticipated stigma has consequences for decision making around HIV disclosure, as it may increase feelings of fear around sharing one's HIV-positive status with other people. Specifically, disclosure of an HIV-positive status may be inhibited if someone fears that other people will reject them upon learning this information (Derlega, Winstead, Oldfield & Barbee, 2003). Finally, internalised stigma has shown a significant negative correlation with psychological wellbeing for people living with HIV, on a self-report measure examining satisfaction with life and experience of low mood (Mak, Poon, Pun & Cheung, 2007).

HIV Disclosure. Paediatric HIV disclosure is the process in which children with PAH are told about their diagnosis by a caregiver or healthcare professional (Evangeli & Kagee, 2016). WHO guidelines (2011) specify that children should gradually be given information regarding HIV, appropriate for their cognitive and developmental level, in a process which facilitates full disclosure by the age of 12

¹ 'HIV status' is shorthand for 'Perinatally acquired HIV-positive status' in all chapters, unless stated otherwise.

years old. Full paediatric disclosure constitutes the child being made aware that they have an illness and this illness being named as HIV (Evangelis & Kagee, 2016).

Full disclosure enables an individual to subsequently make decisions about sharing their HIV-positive status with other people. A 'direct disclosure' is defined as the HIV-positive person directly telling a target person about their status (Préau et al., 2015). Other types of disclosure are 'indirect disclosure' (the HIV-positive person's status is shared with the target person by someone else who knew it) and 'guessed disclosure' (someone seeks confirmation of their hypothesis that the individual is HIV-positive) (Préau et al., 2015).

There has been much variation in reported rates of direct disclosure by HIV-positive individuals. The literature indicates that up to 50% of HIV-positive youth have not shared their status with anyone outside their immediate family (Lee & Oberdorfer, 2009). A review paper estimated rates of direct disclosure (not specified by type of recipient) as between 22% and 65% percent for HIV-positive young people under 25 years old (Thoth, Tucker, Leahy & Stewart, 2014).

There may be physical health benefits of HIV disclosure for young people living with HIV. Sherman et al. (2000) found that children (living with PAH or HIV acquired via blood transfusion), who had shared their HIV-positive status with friends in the past year had a significantly greater increase in their CD4 count than those who had not yet disclosed. Whilst this effect remained significant after controlling for level of medication, findings were correlational rather than causal. Being in good health (as indicated by high CD4 count) may also be indicative of other

factors which increase confidence around sharing one's HIV-positive status, such as feeling informed about the diagnosis.

The Disclosure Processes Model. A Disclosure Processes Model (DPM) of decision making around sharing a concealable stigmatized identity (Chaudoir & Fisher, 2010) has been applied to understanding disclosure in HIV populations (Chaudoir, Fisher & Simoni, 2011). The DPM proposes four key components to HIV disclosure (Chaudoir et al., 2011). The process begins with antecedent goals for disclosure, which are either 'approach goals' or 'avoidance goals'. 'Approach goals' are those in pursuit of positive outcomes from disclosure, such improved relationships; whilst 'avoidance goals' are those intended to prevent negative outcomes from disclosure, such as rejection or stigma. The second component is the disclosure event itself, which involves the person's verbal communication of their HIV-positive status to a confidant and the confidant's subsequent reaction. The model proposes that these two components and the antecedent goals are all linked: people with approach goals are more likely to effectively communicate the information which results in a positive reaction from the confidant, whereas people with avoidance goals are less likely to use effective communication strategies and therefore receive neutral or even negative responses from the confidant. Mediating process and outcomes are the third component in the DPM. The authors propose that a disclosure decision has outcomes on an individual, dyadic and social level. The individual outcome is mediated by how much the disclosure may alleviate the psychological cost of suppressing information, the dyadic outcome is mediated by

how much the disclosure elicits social support from the confidant and the social outcome is mediated by how much the disclosure influences wider societal perceptions of HIV. The final element of the model is the feedback loop, accounting for how each disclosure event affects the next disclosure decision. A positive disclosure experience is proposed to increase how open a person will be about their HIV-positive status in the future, whereas a negative experience will result in increased secrecy around their HIV-positive status (Chaudoir et al., 2011).

HIV disclosure has been described as a selective process in adult HIV populations. Chaudoir et al. (2011) used the DPM as a framework to review the literature on HIV disclosure, and found that the highest rate of disclosure by HIV-positive individuals was to confidants who were also HIV-positive. A survey of HIV disclosure patterns completed by 2,932 HIV-positive adults in France (minimum age of 18 years old), revealed that direct disclosure was most frequent to friends and siblings (amongst a group of 'significant others' constituting: parents, siblings, children, other relatives, friends and colleagues) (Peretti-Watel et al., 2006). Direct disclosure to one significant other also increased the likelihood of disclosure to more significant others (Peretti-Watel et al., 2006).

In relation to the current study, the DPM should be considered in the context of additional factors associated with the age of the UK PAH population. This population is now entering adolescence, which represents a time when young people are particularly sensitive to rejection (Wiener & Battles, 2006). This sensitivity may consequently increase the perceived risk of sharing their HIV status for the PAH population. Young people are also spending more time with their

friends, establishing deeper friendships and making decisions about romantic relationships (Hartup, 1996) during adolescence, all of which may influence disclosure decisions. HIV-positive youth aged 17 to 19 years old have reported that their feelings of autonomy (which are developing during adolescence) were supported when their disclosure decision was respected, but thwarted if their status was shared without their consent (Gillard & Roark, 2013).

Research on HIV disclosure in the PAH population reveals the practical techniques this group are using, within the disclosure processes outlined by Chaudoir et al. (2011). In a study of how young adults (aged 18 – 23 years old) living with PAH manage disclosure in intimate relationships, participants described testing the likely reactions of their partner and using this information to decide whether or not to share their status (Greenhalgh, Evangelii, Frize, Foster & Fidler, 2016). Techniques included asking questions to determine their partner's knowledge of HIV, establishing their partner's attitudes towards HIV and proposing hypothetical questions about knowing someone who is HIV-positive. The authors hypothesise that employing these strategies enabled young people living with PAH to feel in control of the disclosure process, as they could make informed judgements about the risk of rejection post-disclosure (Greenhalgh et al., 2016).

Family Context. The PAH populations' experience of living with HIV is "uniquely embedded in a familial context" (Calabrese et al., 2012, p. 2). Children living with PAH experience high levels of family pressure not to reveal their HIV status (Michaud et al., 2009), as doing so unavoidably reveals their mother as being

HIV-positive too. A young person sharing their PAH status could also raise questions about the HIV status of wider family members (Vreeman et al., 2010). HIV-positive mothers have reported their primary concerns around paediatric disclosure to be the risk of the child revealing the maternal HIV status and the family subsequently being exposed to discrimination and enacted stigma (Waugh, 2003). The burden of keeping family secrets regarding HIV status may have negative implications for the young person's own wellbeing though. Being asked conceal their HIV status at an early age to protect other family members could trigger the internalisation of shame around being HIV-positive for the PAH population (Sherman et al., 2000).

Medication. The PAH population are exposed to physical health risks as a consequence of long-term ART (Hazra, Siberry & Mofenson, 2010). These include central nervous system abnormalities, increased risk for cardiovascular disease, renal complications and also reduced bone density (Hazra et al., 2010). The PAH population may also make behavioural adaptations to disguise their medication use, as they grow up living with HIV (Calabrese et al., 2012). In an American PAH population aged 11 to 18 years old, disclosure of HIV status to at least one friend was associated with less medication hiding than disclosure to no friends (Calabrese et al., 2012).

Neurodevelopment. The advent of ART has significantly reduced the prevalence of neurological difficulties in young children living with PAH (Smith & Wilkins, 2015). A particular neurological profile has been identified, however, for

the older PAH population who did not receive ART until later in the disease trajectory. Research suggests this group perform less well than their non-HIV positive peers on measures of processing speed and visual-spatial tasks (Laughton et al., 2013).

Mental Health. In a sample of young people living with PAH (aged 13 – 24 years old), 55% of the sample were identified as having at least one psychiatric diagnosis and the most common of these diagnoses was a mood disorder (Kapetanovic et al., 2011). Young people living with PAH have been identified as experiencing more behavioural and emotional difficulties than HIV-negative youth too (Mellins & Malee, 2013). In an American study examining PAH and wellbeing in young people aged 5 – 18 years old, the PAH group scored worse on measures of quality of life and anxiety than age matched HIV-negative youth (Bomba et al., 2010).

Overall, however, a review paper of the mental health of the PAH population concludes that these young people actually experience reasonable mental health (Mellins & Malee, 2013) despite the numerous risk factors associated with managing a chronic and stigmatised health condition (highlighted in this introduction) which could be detrimental to their wellbeing. Evidence suggests that the PAH population have a similar (Gadow et al., 2012) or lower (Malee et al., 2011) prevalence of mental health difficulties when compared with youth from HIV-affected households (defined as youth who were perinatally exposed to HIV but uninfected and HIV-negative youth who have an HIV-positive family member). A comparison of anxiety and depression symptoms for young people aged 13 – 21 years old with PAH and

their HIV-negative siblings in the UK found no significant differences between the two groups (Le Prevost et al., 2015).

It appears therefore, that being HIV-positive may not be the mechanism for the mental health difficulties seen in some PAH samples (Mellins & Malee, 2013). Psychiatric morbidity for the PAH population may be better understood as a biopsychosocial formulation of numerous other predisposing factors (Rao et al., 2007). In addition to factors outlined so far, other potential stressors for the PAH group may include death of a parent, family financial difficulties (Peterson et al., 2010) and living in disadvantaged neighbourhoods (Kang, Mellins, Dolezal, Elkington & Abrams, 2011).

Adolescence and Emerging Adulthood

Advances in medical care for people living with HIV have been reflected in the long term survival and increasing age of the UK PAH population. Previously not expected to live beyond childhood, over 65% of the UK PAH population is now aged 15 years or older (CHIPS, 2015). The PAH population are therefore entering a transitional developmental phase of adolescence and young adulthood in the context of living with a chronic and stigmatised health condition. The PAH specific factors they face have been outlined, so attention will now briefly be given to understanding the context of adolescence and young adulthood. The focus will be on friendships which are presented as one particularly important aspect of the adolescent and young adulthood period.

Adolescence is a process of physical and emotional maturation, which has been conceptualised as involving two transitional phases: the first from childhood to early adolescence and the second from later adolescence to adulthood (Kang, Mellins, Ng, Robinson & Abrams, 2008). The WHO (2016) define adolescents as young people between the ages of 10 – 19 years old. Arnett (2000) proposed “emerging adulthood” as an additional and distinct phase of development which occurs between the ages of 18 – 25 years old. During emerging adulthood young people explore a range of possibilities for their lives, ultimately making choices which determine their future (Arnett, 2000). Identity formation during this phase includes a young person exploring possibilities (Marcia, 1966) for love, for work and forming opinions about the world (Arnett, 2000) before aligning their identity with a particular set of values, beliefs and aspirations (Marcia, 1966). Risk taking behaviours are also characteristic of this period, thought to be exacerbated by increased sensation seeking and the desire to obtain a range of experiences (Arnett, 1994). Emerging adulthood has been described as a time of “profound change and importance” (Arnett, 2000, pg. 1) after the dependent roles of childhood end and before the responsibilities of adulthood begin. In a survey of over 300 college students, ‘accepting responsibility for one’s self’ and ‘making independent decisions’ were identified as characteristics that would indicate adulthood had been reached (Arnett, 1997).

The converse of being so free for exploration is that emerging adulthood involves instability in many domains. Changes in residential setting and switching from education to employment occur frequently during this time, alongside changes

in demographic status such as getting married (Arnett, 2000). Socio-economic opportunities may also be influential to the changes involved in emerging adulthood period. For someone who has little access to education or training, the phase of emerging adulthood may be shorter if they embark more quickly on 'adult' tasks such as marriage and parenthood (Arnett, 2000). In working class families the emphasis may be on securing employment rather than a lengthy period of identity exploration (Arnett, 2000) and there is also much cross-cultural variation in beliefs about emerging adulthood, for example how long adolescent boys or girls should remain in the family home before marriage (Arnett, 2012).

Emerging adulthood occurs against a background of physical development (Kang et al., 2008) including expansion of the neural system, increased secretion of hormones and bodily changes during puberty (Cameron, 2006). Piaget's (1955) Theory of Cognitive Development also describes the 'imaginary audience' phenomenon in which young people increasingly observe and interpret the behaviour of others during adolescence. The young person infers what other people may be thinking or feeling, and therefore what the other person thinks of them too. The result is that the adolescent feels as though an imaginary audience is judging them. A secondary consequence of increasingly interpreting other people's behaviour is that a young person inevitably makes comparisons between themselves and other people, namely their peers. This could increase risk-taking behaviours, if the young person overestimates their own abilities compared to others. Alternatively, feelings of depression may arise if the young person's comparisons result in them drawing unfavourable conclusions about themselves.

Friendships

Friendships and interactions with peers are integrated in to the developing identity of the young person during adolescence and young adulthood (American Academy of Paediatrics, 2013). Friendships become increasingly close (Berndt, 2004) as peers become an important resource for exchanging thoughts, feelings and experiences. Adolescence is also a time of tension between independence and connectedness for the young person though (Kang et al., 2008) as they negotiate a process of 'progressive independence' away from their family and towards their peers (Olsen & Sutton, 1998). The situational hypothesis (Brittain, 1968) proposes that during progressive independence, the level of parental or peer influence varies between each domain of the young person's life. Parents are proposed to have more influence over areas which affect the young person's future (such as education and career plans) whereas the influence of friends is greater in day-to-day domains (such as choices about leisure time) (Meeus, Oosterwegel & Vollebergh, 2002). The overall goal of progressive independence is for the young person to increase their autonomy away from their parents and towards their peers in all domains (Olsen & Sutton, 1998).

A position of 'extreme peer orientation' has been identified in research examining the changing relationships between young people, their parents and their friends during adolescence (Fuligni & Eccles, 1993). This involves an adolescent sacrificing their school success, wellbeing and adherence to parental rules with the aim of aligning themselves as closely as possible to their peers (Fuligni & Eccles, 1993). The quality of the parent-adolescent relationship is also influential, with

adolescents more likely to orient themselves with peers if their parents are perceived to be restrictive and do not involve the young person in decision making (Fuligni & Eccles, 1993).

Various theories can be applied to understanding the underlying processes in adolescent friendships. Attachment Theory (Bowlby, 1958) suggests the relationship with the primary caregiver during childhood forms the template for other relationships, including friendships, that a person forms later in life. Zimmermann (2004) completed the adult attachment interview with 43 adolescents to examine the relationship between attachment and adolescent friendships. A secure attachment style was significantly related to having close friendships and being integrated in a peer group.

Self Determination Theory ([SDT] Ryan & Deci, 2000) can also provide an explanation of adolescent friendships. SDT proposes that autonomy, competence and relatedness are basic human needs that form the basis for self-motivation and personality development. Achieving a position where these needs are being met can be facilitated or thwarted by social context (Ryan & Deci, 2000). The adolescent is therefore tasked with establishing a balance between autonomy and relatedness with regard to friendships. They are required, for example, to learn how to assert their newly acquired opinions about the world (autonomy) whilst understanding and validating the opinions of others (connectedness) (Chango, Allen, Szewedo & Schad, 2015). Research has demonstrated that an inability to establish autonomy and connectedness within friendships (assessed by self-report measures and researcher observations) aged 13 years old predicts lower peer-rated friendship competence,

increased depressive symptoms and social withdrawal aged 18 years old (Chango et al., 2015).

Theories of adolescent friendships also distinguish between cliques, defined as small groups of close peers spending a lot of time together; and larger crowds which hold a more collective identity based on a particular shared interest (Brown, 1990). Early theories (see Sullivan, 1953) of friendships propose that dyadic friendships may become more important than wider peer group acceptance during adolescence. Low levels of conflict combined with high levels of companionship, support, and closeness have been identified as the optimum characteristics of dyadic friendships for adolescents (Laird, Pettit, Dodge & Bates, 1999). These friendships can offer intimacy, social support in times of crisis and also facilitate development of other skills such as problem solving in the context of peer relationships (Laird et al., 1999). A longitudinal study with a group of 618 American adolescents (mean age 15.1 years old) examined the relationship between friendship and emotional adjustment (Demir & Urberg, 2004). Positive friendship quality within a best friendship (assessed on likert scale ratings of companionship, conflict, help, security and closeness) was the best predictor of adjustment in this population.

The long-term physical health benefits of having close adolescent friendships have also been highlighted in the literature. In a longitudinal study assessing young people over a 14 year period (between the ages of 13 - 27 years old), close friendships in early adolescence significantly predicted physical health quality in adulthood (Allen, Uchino & Hafen, 2015). Acquiescence to norms within a friendship group, described by the authors as 'being a follower' and 'prioritising collective

values', was a second predictor of better physical health in adulthood (Allen et al., 2015). These effects remained after controlling for a number of other factors including existing health problems, mental health symptoms and demographic characteristics.

Accessing Support from Friends

One explanation for the positive effect of friendships on wellbeing during adolescence and early adulthood (Ueno, 2005), could be that friends increasingly serve a supportive function as young people increase autonomy away from their parents (Hartup, 1996). Social support can be emotional (expressions of empathy and caring), instrumental (tangible help) or informational (offering information and advice) (Glanz, Rimer & Viswanath, 2008). The Sensitive Interactions Theory (Barbee & Cunningham, 1995) offers one hypothesis for how adolescents and young adults might access social support from their friends. This theory distinguishes between methods of direct and indirect support activation. Direct support activation involves asking for help, either by detailing the problem or using overt non-verbal communications of distress such as crying. Indirect support strategies are broader verbal hints that a problem exists and more general non-verbal indicators of negative affect such as sighing (Barbee, Rowatt & Cunningham, 1998).

Accessing support is a relational process influenced by both the seeker's support activation behaviours and the supporter's willingness or ability to deliver that support (Barbee & Cunningham, 1995). The seeker's behaviour can be

conceptualised as involving 'approach' or 'avoidant' coping styles (Roth & Cohen, 1986). Approach coping involves direct efforts to maintain control of a situation and solve a problem, whereas avoidant coping involves withdrawal from a situation and techniques to distract from the problem (Roth & Cohen, 1986). The Interactive Coping Typology of Social Support Theory (Barbee et al., 1998) provides further explanation of the different support seeking behaviours a person may display. The four categories are: solve behaviours (to answer the problem), solace behaviours (to elicit positive emotions from others), dismiss behaviours (to avoid the significance of a problem) and escape behaviours (to engage in emotion focused avoidance of the problem).

These are all possible mechanisms by which adolescents and young adults may access the support they need from friends as they negotiate this developmental stage.

Friendships and Social Support in Chronic Health Conditions

Peer relationships and social support from friends during adolescence and young adulthood have an added significance in the context of a chronic health condition (La Greca, Bearman & Moore, 2002). Firstly, adolescents living with chronic illnesses have to cope with disease-specific challenges in addition to the other challenges of this developmental phase (Rassart et al., 2012). This population are also growing up experiencing reciprocal interactions between development and illness. Chronic illness can impair the biological features of adolescent development (by affecting puberty), may hinder psychological development (due to associated

cognitive impairments or disruptions to identity formation) and can also limit social development (by restricting independence or opportunities to socialise). Conversely, the adolescent period of development can affect the chronic illness in all of these domains too. Biologically this might occur through hormonal changes, psychologically it could present as difficulty adapting to autonomous illness management and socially it may involve the adolescent engaging in risky or unhealthy behaviours which are detrimental to effective management of the chronic health condition (Suris, Michaud & Viner, 2004).

Adolescents living with chronic illnesses may also struggle with feeling different from their healthy peers during adolescence (Suris et al., 2004). Applied to the context of chronic health conditions, the 'extreme peer orientation' of adolescence may include sacrificing health outcomes to maintain peer relationships (Drew, Berg & Wiebe, 2010). The young person may ignore or rebel against parental advice about disease management (Drew et al., 2010). Research in to young people's management of Type 1 Diabetes Mellitus, for example, found that accommodating friends becomes more of a priority than adherence to treatment regimen during adolescence (Wysocki & Greco, 2006).

Support from friends has been shown to moderate the relationship between adolescence and illness though. Primarily, friendships have benefits for psychological health (Helgeson, Reynolds, Escobar, Siminerio & Becker, 2007) through provision of emotional support. Group identities that promote health behaviours may be especially valuable (La Greca et al., 2002), as risk taking behaviours such as smoking

or alcohol use can increase during adolescence (Bachman, Wadsworth, O'Malley, Johnston & Schulenberg, 1997) which may be detrimental to physical health.

Research from Other Chronic Health Conditions on the Role of Friendships

Research has highlighted the role of friendships in the context of adolescence and specific chronic illnesses. Friends were reported to offer a variety of support during interviews with American adolescents living with type 2 diabetes mellitus (T2DM) (Brouwer et al., 2012). Two themes identified from the data were support for diabetes-specific behaviours (such as reminders about dietary restrictions) and support for non-diabetes behaviours (such as doing age typical activities not associated with the diagnosis). Support which is unrelated to the diagnosis may have an important secondary role in normalizing the young persons' experience and helping them to feel accepted (Kyngäs, 2004). The third theme was experiencing a feeling of belonging which incorporated feeling connected with, and understood by, friends who also had T2DM. The final theme was disclosure, with participants reporting that they would share their diagnosis with friends for safety reasons, to educate peers and also to elicit support (Brouwer et al., 2012).

Evidence from adolescent populations living with health conditions which are also present from birth may be more helpful to facilitating an understanding of the PAH population. Kyngäs (2004) interviewed adolescents living with a range of chronic conditions, including diagnoses present from birth (35% Type 1 diabetes mellitus, 30% asthma, 20% epilepsy, 15% juvenile arthritis), about the support they accessed from friends. Adolescents distinguished between peers who had the same

chronic illness and those who did not have any chronic illness. Friends with the same diagnosis were reported to be easy to talk to, attributed to the adolescents being able to understand each other's situation without any need for explanation (Kyngäs, 2004). Support from other young people with the same diagnosis was highly valued by adolescents, although feelings were mixed if that other person was experiencing complications associated with their condition (Kyngäs, 2004). Some participants reported that they may helpfully learn something from that friend's experience, whereas others felt that seeing their friend unwell may cause depression or feelings of fear (Kyngäs, 2004). Friends who did not have a chronic illness were described as being supportive in all domains of life for the adolescent. This did include support to cope with their illness, however topics of discussion with these friends were more frequently non-disease related than discussions with other sufferers.

Adolescents' experiences of support from friends has also been compared with support they receive from parents. Young people (aged 13 – 18 years old) living with Type 1 Diabetes Mellitus reported perceiving their friends more positively than their parents (Carroll & Marrero, 2006). These adolescents described the overbearing nature of parents who were unwilling to relinquish disease management to the child. In contrast, friends were viewed as a supportive safety mechanism who could provide help if or when any difficulties arise with managing the condition (Carroll & Marrero, 2006). Increasing autonomy is a heterogeneous process though (Arnett, 2000), which may result in much variation within adolescent populations around perceptions of parental support.

Friendships have also been identified as supportive for identity formation in the context of chronic illness during adolescence. Rassart et al. (2012) compared friendship quality and identity formation for adolescent chronic heart disease (CHD) patients (aged 15 – 20 years old) and a control group of adolescents from the community in Belgium. The results indicated that positive peer relationships were one facilitator of identity formation in young people living with CHD (Rassart et al., 2012). The CHD group reported higher quality of peer relationships than the control group too and the authors propose the Response Shift Phenomenon (Rapkin & Schwartz, 2004) as one theory to explain this result. The Response Shift Phenomenon (Rapkin & Schwartz, 2004) proposes that receiving a diagnosis of a chronic illness induces a shift in the internal values a person holds, consequently causing them to appraise quality of life (including peer relationships) differently. This shift occurs in three ways, explained here using examples from the context of HIV and friendships. One shift is a reconceptualisation of the elements which are perceived to be part of a particular construct, for example what constitutes a good friendship. A second shift is a reprioritisation of which parts of the construct are important, for example spending time together or having trust within a friendship. The third shift is a recalibration of how the person rates their own health status in relation to the health of others, for example comparing being HIV-positive to other health needs that friends might have.

The structure of healthcare systems (in the UK, for this study) should also be acknowledged when considering how much young people with chronic illnesses might access support from friends. Late adolescence is the time when patients

transition from child to adult medical services. This may result in patients losing long-standing sources of support in the paediatric team (Rassart et. al, 2012). Compounded by the corresponding increase in responsibility for their own care, there is a risk of young people disengaging with services during this transition (Mofenson & Cotton, 2013). The role of friends, and the support they may offer, may be even more important during this transitional phase.

Emerging Literature on Friendships and PAH

Literature is emerging which has specifically investigated the friendships of young people living with PAH. Abramowitz et al. (2009) investigated the social support experiences of young people with HIV (aged 13 - 21 years old) in a sample constituting both PAH and BAH participants. Quantitative results from this study provided some indication about the type of friendships the PAH group (n=99) had. This population report a greater number of close friends and also more HIV-positive friends than the BAH group (Abramowitz et al., 2009). Young people with PAH also report greater satisfaction with the help provided by friends than young people who have BAH (Abramowitz et al., 2009). The PAH group report having significantly fewer friends who know their HIV status though (Abramowitz et al., 2009). This study provides initial quantitative data about the friendships of the PAH population. Further research is necessary though to examine other dimensions of friendship beyond just how many friends the PAH population have (Calebrese et al., 2012). The mechanisms for how friends provide support and the decision making around

sharing one's HIV status with friends are two areas in particular which may be important to the friendship experience of young people living with PAH.

Abramowitz et al. (2009) also report that social support from friends, in the form of emotional support in particular, was associated with fewer depressive symptoms in HIV-positive adolescents and young adults. Support from friends was significantly correlated with better functioning over a three year period in an earlier study of adolescents living with PAH (aged 13 – 24 years old) (Wiener & Battles, 2006). Further investigation of social support for the PAH group alone, rather than in comparison or combination with the BAH group, is necessary to understand more about friendships and wellbeing for the PAH population.

For the PAH population, accessing social support also involves the additional consideration of whether they might encounter stigma if they choose to share their status during that process. Having more than one close friend and having friends who continued to socialize with the young person post-disclosure (after the HIV-positive person shared their status) has been associated with higher levels of perceived social support in the PAH population (Lee, Yamazaki, Harris, Harper & Ellen, 2015). Researchers have hypothesised that disclosure of HIV status to friends may be the key factor facilitating the relationship between social support and improved psychological functioning (Wiener & Battles, 2006). Exploring the mechanisms through which HIV and friendships may be related has been highlighted as key to advancing our understanding of social support for young people living with HIV (Abramowitz et al., 2009). Closeness of friendships and circumstances

surrounding disclosure within friendships have specifically been cited as valuable areas for examination (Calebrese et al., 2012).

Emerging research (Mupambireyi, Bernays, Bwakura-Dangarembizi & Cowan, 2014) with the PAH population in sub-Saharan Africa has highlighted the beneficial effects of peer support groups. In Zimbabwe, 26 children (aged 11-13 years old) living with PAH completed in depth interviews and a focus group about their experiences of PAH support groups. Children reported support groups to be a 'safe social space', where they felt accepted and could play with other children without fear of discrimination (Mupambireyi et al., 2014). Children also described that attending the peer support group helped them realise they were not the only children living with PAH (Mupambireyi et al., 2014). The authors found that this confidence translated to children becoming less withdrawn outside of the support groups too, corroborated by feedback from carers (Mupambireyi et al., 2014). This research was conducted with children who are younger than the adolescent and emerging adulthood ages that have been the focus of this introduction. The findings on the benefits of peer support, such as opportunity for play, consequently refer to normative activities of an earlier stage of development. This invites questions about whether the normalising and beneficial effects of having peers with the same diagnosis continue to be present and valuable for young people living with PAH during adolescence and emerging adulthood. One study examining the social experiences of young people living with PAH in South Africa (aged 14- 16 years old) reported that this population have an 'embedded' social network, defined as a naturally occurring social network consisting of other people who are also HIV-

positive (Peterson et al., 2012). Participants reported that they were able to integrate both the social and supportive function of friends in these networks (Peterson et al., 2012).

Applying Existing Research to Understanding the Friendship Experiences of the PAH Population

The need for more research investigating the specific experiences of the PAH population has been discussed. Limitations of the existing literature and the difficulties of generalising this to understanding the unique experiences of the PAH population have also been highlighted. There are other notable limitations in the existing literature which mean current findings do not contribute to an increased understanding of friendship experiences in the PAH population.

Research on the transition to adulthood for young people with PAH often focuses on the medical trajectory of HIV as an outcome measure (Mellins & Malee, 2013). Whilst this is important information for the management of a chronic health condition, investigating medical outcomes in isolation from psychosocial factors, such as friendships, is a significant limitation of the research. A more holistic understanding of this population is particularly necessary because PAH is disproportionately represented in populations from urban environments and minority ethnic groups in Western countries (Kang et al., 2008) where they may be many other factors contributing to their experiences. Increased qualitative investigation of psychosocial factors relevant to the experience of this population will also enable further links to be made between the domains of psychological and

physical health which can inform the care of young people living with PAH.

Understanding more about the mediating role of peer relationships in the health of the PAH population (La Greca et al., 2002) is one way of achieving this goal. Pichon, Rossi, Ogg, Krull and Griffin (2015) additionally note that existing literature often focuses on family support for young people living with HIV, and therefore that increased understanding of support from other social domains is needed.

Finally, conducting HIV research in countries such as the UK where there are sufficient resources to do so is part of the shared responsibility for global HIV care (Agwu & Fairlie, 2013).

The Proposed Study

Adolescence through to emerging adulthood is a period of maturation, when the young person is tasked with developmental challenges including identity formation and achieving independence from their parents. Obtaining an understanding of how young people with PAH experience these tasks, in the context of concurrent challenges around living with a stigmatised chronic illness, is essential to informing medical teams and the individual's wider network about how best to support them.

Friendships have been identified as an important and influential resource for young people as they navigate adolescence. The literature also suggests that friends can be a source of support for young people who are living with a chronic illness during this developmental phase. Research with adolescent cardiac disease and diabetes populations has highlighted how friends offer both disease specific and

non-disease related support in a variety of formats. The literature also suggests there are differences between friendships with other young people who do or do not have the same diagnosis. To date, this research has not been matched with research on the friendships of the adolescent and young adult PAH population. This is partly because the current generation of PAH youth are amongst the first to survive to adulthood, so existing research is limited in quantity. It is also because research which has been published either combines the PAH group with BAH youth, or offers solely quantitative data regarding their friendships. As this introduction has highlighted, there are many elements to the experience of the PAH population, and these complexities may not be fully captured by quantitative measures. Examining if, and potentially how, PAH specific factors such as stigma and HIV disclosure decisions interact with normative friendship processes warrants further investigation.

To address these limitations, recognising the need to increase our understanding of the PAH populations' experiences during adolescence and emerging adulthood, and informed by the importance of peer relationships at this age, the proposed study aims to explore and present a model of the experiences of friendships for young people living with PAH.

To explore how participants perceive the numerous potential influences on their friendships and anticipating the complexity of this phenomenon, a qualitative methodology will be used. Semi-structured interviews will be conducted with young

people living with PAH to examine which factors are perceived to influence the development of friendships, as well as how having PAH is perceived to influence the nature of friendships. Further questions will gather information about decisions around disclosure of HIV status, the influence of family HIV status, different types of friendships (with HIV-positive or HIV-negative young people) and the types of support these friends might offer. Data collected will be used to propose a model of friendships for this population, following a Grounded Theory methodology (Charmaz, 2014) which is appropriate for the study of social experiences. It is hoped that this model can subsequently inform clinical work supporting the wellbeing of young people living with PAH as they transition into adulthood.

Aim and Research Questions of the Proposed Study

The aim of this study is to explore, and create a model of, the experience of friendships for young people living with PAH. The research questions are:

What is the experience of developing friendships for young people living with PAH?

How does the HIV status of friends influence the friendships of young people living with PAH?

What are the perceived effects on friendships of having a mother who is HIV-positive, for young people living with PAH?

What factors are perceived to influence the decision of a young person living with PAH to disclose or not to disclose their HIV status to friends?

How do young people living with PAH experience sharing their HIV status with friends and how does sharing their HIV status or not subsequently affect the friendship?

Chapter 2: Method

Research Design

A cross-sectional qualitative design was used to conduct and analyse data from semi-structured interviews with nine young people living with PAH.

Choice of Methodology

Qualitative Methods. The aim of this study was to explore, and create a model of, the experience of friendships for young people living with PAH. Research questions examining social processes and construction of meaning within those processes are best answered using a qualitative methodology. A qualitative approach facilitates exploration of how friendships are established and maintained in the context of being HIV-positive. This methodology also elicits more data on the lived experience of decision making, affect and cognitions surrounding this process for the PAH population than stand-alone quantitative measures would provide.

Grounded Theory Methodology. Following consideration of the qualitative approaches available, a Constructivist Grounded Theory methodology (Charmaz, 2014) was selected. Grounded Theory has been proposed as the most appropriate methodology for the study of social experiences and research aiming to generate theories that explain these processes (Lingard, Albert & Levinson, 2008).

Selection of Grounded Theory over other qualitative methodologies. Given the limited existing research on friendships during adolescence and emerging

adulthood for the PAH population, the inductive approach of Grounded Theory was considered the most appropriate methodology for this study. Grounded Theory (Charmaz, 2014) also lends itself to the examination of open ended research questions (Tweed & Charmaz, 2012), used in this study. Research in a novel area, such as PAH and friendships in young adulthood, requires the data to guide any emerging theory. Grounded Theory was therefore selected as more appropriate than other qualitative approaches that require additional interpretation by the researcher and go 'beyond the data' (Charmaz, 2014). Finally, Grounded Theory methodology facilitates the construction of a theoretically grounded model to explain the examined phenomenon. Using this methodology therefore achieves the study aim of producing a model of the friendship experiences of young people living with PAH.

Other qualitative approaches were reviewed but evaluated as unsuitable for addressing the research questions and aims of this study. Narrative methodology (Polkinghorne, 1995) examines how an individual's story of events in their lives can help them understand their own experiences, so would not best answer research questions which have a relational focus on friendships. Interpretative Phenomenological Analysis (IPA) (Smith, 2004) also examines the individual's personal interpretation of an event and is not designed to provide broader conclusions about that event. This research aims to combine participants' individual experiences to produce a model understanding the friendships of young people with PAH, which an IPA approach would not facilitate. The predominantly descriptive approach of Thematic Analysis (Braun & Clarke, 2006) or the focus on construction of

language in Discourse Analysis (Fairclough, 2013) would not facilitate the production of a model either.

History of Grounded Theory. Glaser and Strauss' (1967) publication of a Grounded Theory methodology marked the formalisation of qualitative research approaches. The methodology encompassed both Glaser and Strauss' epistemological positions. The former favoured the systematic approach of coding and analysis to inform emerging theories; the latter highlighted individual agency and emphasised how social meaning is created through peoples' interactions with each other. The key principles of this "systematic yet flexible" (Charmaz, 2014 p.1.) methodology are: taking an inductive approach and being guided by the data (see analysis section for detail).

Divergent Grounded Theory. Glaser and Strauss went on to develop their Grounded Theory methodology in 'divergent' directions (Charmaz, 2014). Strauss and colleagues (Strauss & Corbin, 1990) moved Grounded Theory methodology towards comparing data for the purpose of verification. They proposed increasingly technical analytic strategies, instead of the data led emergent methods of early Grounded Theory analysis (Charmaz, 2014). Glaser remained aligned to the original Grounded Theory principle that the methodology was one of discovery from the data (Charmaz, 2014). Strauss and Corbin's (1990) methodology became increasingly popular, to the extent that Grounded Theory became known as a positivist methodology during the 1990s (Charmaz, 2014).

Constructivist Grounded Theory. Critics of both Glaser and Strauss' (1967), and Strauss and Corbin's (1990), Grounded Theory methodologies accuse the approaches of relying on metanarratives about human nature and encouraging the authoritative role of the researcher (Charmaz, 2014). To address these criticisms, and with the aim of moving Grounded Theory away from the positivist position, a Grounded Theory methodology that incorporated a more flexible 'constructivist turn' was developed (Charmaz, 2014). The inductive approach of the original methodology was maintained, but the Constructivist Grounded Theory proposed by Charmaz (2002) differs from traditional Grounded Theory by incorporating the assumption that the research itself is a constructed social reality. Charmaz (2002) highlights the role of the researcher and the subjectivity they bring to the process through their own position, perspective and values. These are proposed as influential in both the researcher's interaction with the participant and also the analysis of data. Glaser and Strauss (1967) referred to discovering a theory that solely emerges from the data, whereas Charmaz (2014) argues that the theory is a constructed reality, interpreted under the influence of both the researcher's and the participant's experiences (Charmaz, 2014).

Sensitivity to the Data. Grounded Theory methodology traditionally dissuades researchers from becoming familiar with the existing literature, to ensure preconceived hypotheses do not influence how they interpret or prioritise themes within the data (Charmaz, 2014). The requirements of doctoral research include

submitting a literature review in advance, limiting adherence to this aspect of grounded theory methodology. It has been argued that most researchers will be somewhat familiar with the topic when embarking on Grounded Theory research (Ramalho, Adams Huggard & Hoare, 2015) though and reflexivity (see research quality section) is the key to controlling any potential influence this may have (McGhee, Marland & Atkinson, 2007).

Development of the Study

Ethical Approval. Ethical approval for this research was received from the London Camden and King's Cross NHS Research Ethics Committee (REC) (Appendix 1), the Psychology Department Ethics Committee of Royal Holloway University of London (Appendix 2) and from the Research and Development Department of both NHS Trusts in which recruitment took place (Appendix 3). The REC approved a subsequent substantial amendment (Appendix 4) increasing the voucher payment to participants from £10 to £15 (when additional funding became available). Recruitment only began after this amendment had been approved, to ensure all participants received equal payment.

Interview Schedule. The interview schedule (Appendix 5) was collaboratively developed by the researcher and both (field and academic) supervisors. It was agreed that a chronological approach to the interview, from paediatric disclosure to the present day, would best facilitate an investigation of friendship experiences throughout adolescence and emerging adulthood.

The interview schedule was designed to contain open questions that would facilitate an exploration of participants' experiences: *"In your experience, how has living with HIV affected your friendships?"* Specific prompts were included to gather more detail where necessary: *"What were the reasons you decided not to tell them about your HIV status?"* The interview schedule was semi-structured, to collect data for each research question whilst remaining flexible to be guided by conversations on the day. The interview was role-played with the academic supervisor (experienced in clinical work with HIV populations) before recruitment began, to clarify phrasing of the questions and also provide feedback on the researcher's interview technique.

Service User Consultation. Feedback was sought on the interview schedule, from a young person (meeting study inclusion criteria) attending a third-sector organisation supporting young people living with HIV. For confidentiality reasons, this was completed anonymously via a member of staff at the organisation. The researcher provided the draft interview schedule along with a brief feedback questionnaire.

The questionnaire asked whether the wording of interview questions was perceived to be sensitive and appropriate, and whether the questions seemed adequate and relevant for examining the friendships of the PAH population. No amendments were suggested and responses indicated that the interview appeared suitably and appropriately worded.

Reviewing the Interview Schedule. Two questions were added during the course of the study. One addressed friendships in the future, after early participants expressed hopes of being able to share their HIV status with friends in due course. The second question asked about support from siblings, when it became apparent that most participants were living at home (see Appendix 5).

Interview questions were written with reference to being 'HIV-positive', as the researcher assumed that using medically accurate terminology would be most appropriate. As interviews were conducted, however, many participants referred to 'my condition' or 'my situation' to describe being HIV-positive. The exact wording of questions was therefore adapted on an individual basis, to reflect the language each participant appeared comfortable with.

Service Setting

Recruitment took place within specialist outpatient clinics for young people living with HIV at two inner London NHS hospitals. Both clinics are run by a multidisciplinary team (MDT) including a Consultant, HIV Clinical Nurse Specialist and a Health Advisor. One clinic also had a junior doctor and both clinics had links with Pharmacy and Psychology services in the hospital. The researcher attended several meetings at both sites to familiarise the MDT with the study and establish a collaborative relationship to facilitate recruitment.

Inclusion and Exclusion Criteria

Participants were eligible to participate in the study if they:

- Had a diagnosis of PAH.
- Were registered as a patient at either clinic where the research was being conducted.
- Had been aware of their HIV status (PAH positive) for at least one year. This was intended to prevent any period of adjustment to the diagnosis from potentially complicating analysis of the data. It was expected that all potential participants would meet this inclusion criteria, given the age range of the study and the WHO (2011) recommendation that paediatric disclosure occurs by age 12 years old.
- Were aged between 16 - 25 years old at time of recruitment. This was intended to capture the focal period of this study, which was adolescence and emerging adulthood.
- Were sufficiently fluent in reading, understanding and speaking English. This was to ensure that participants could give informed consent and so that interviews could be completed without the use of an interpreter. Qualitative research relies on the nuances and meaning within verbal communication, which may be compromised by translation (Charmaz, 2014).

The clinical team were asked to use their judgement to screen potential participants according to two exclusion criteria:

- Any person for whom there were current concerns around self-injurious behavior, to prevent exacerbating any risks to safety.

- Any person for whom participation was deemed likely to be detrimental to wellbeing or exacerbate existing emotional problems, to prevent the risk of causing undue distress.

Sampling

Grounded Theory methodology encompasses a theoretical sampling strategy. Theoretical sampling does not aim to achieve a study sample which is a representative distribution of the population (Charmaz, 2014). Instead, it involves actively trying to recruit participants whose experiences could add to, or clarify, emerging themes in the data (Charmaz, 2014). Theoretical saturation is the end-point at which no new data is emerging and theoretical sampling is not revealing any further contributions to the overall theory.

Due to the very small pool of potential participants (both the UK PAH population and the proportion registered at these clinics), a convenience sampling strategy (Marshall, 1996) of recruiting the most available participants had to be employed. Efforts were made, however, to adhere to the principles of theoretical sampling within this restriction. For example, after the first four participants reported having no experience of sharing their status with friends (or had only done so in an unplanned scenario) the researcher indicated to clinicians that obtaining the experiences of people who had shared their status with friends was a priority for recruitment.

Recruitment

Introducing the study. The consultant (or junior doctor) shared the participant information sheet (Appendix 6) during clinic appointments with patients they had identified as eligible. Clinicians introduced the study to ensure the HIV status of patients who did not go on to participate remained confidential from the researcher. Patients who expressed an interest in the study, met with the researcher who answered any further questions. The option to return for an interview appointment at a later date (travel expenses reimbursed) was provided, but all participants in the final sample chose to stay and complete the interview the same day.

Response rate. One clinic functioned as the primary site for recruitment. This clinic had 86 young people living with PAH registered as patients, 71 of whom were within the study age range criteria of 16 -25 years old. During the recruitment period, 37 of these patients attended clinic appointments. Two patients were identified by clinicians as meeting exclusion criteria, four potential participants did not attend interview appointments, others (quantity unknown) reported to clinicians that they did not have time to participate and one did not want to be audio recorded. Seven patients were recruited from this site to participate in the study. The secondary site for recruitment was a clinic with 43 PAH patients registered (additional data not available). Two participants were recruited from this site. The numerous similarities between the clinics enabled the assumption that participants would not differ based on site of recruitment.

Interviews. Informed consent was obtained in writing by the researcher (Appendix 7) before the interview began. The researcher conducted semi-structured interviews with nine participants, using the interview schedule and providing summaries and reflections of participants' answers throughout. This was to ensure that responses had been understood correctly and to consolidate discussions. Interviews were conducted in a private clinic room and ranged from 50 to 70 minutes in duration. Interviews were audio recorded for transcription by the researcher (then deleted once transcribed). The researcher made notes in a reflective diary after each interview, to capture the process and for reference during analysis.

Debrief. The researcher conducted a debrief at the end of each interview, to enquire about participants' experiences of taking part. Participants were reminded to speak with their clinical team if interviews had highlighted any experiences they might want support with at a later date. Several participants expressed that it had been beneficial and interesting having time to reflect on their friendships.

The interview topic appeared particularly emotive for two participants, although both confirmed during the debrief that they had not felt distressed by the discussions. At the researcher's suggestion, one of these participants spoke briefly with their Health Advisor afterwards. The other participant declined this, but appeared calm at the end of the interview and commented that they had found it helpful to express their feelings about friendships.

Payment. Participants received a £15 shopping voucher as compensation for their time.

Participant Characteristics

Participants completed a brief demographic questionnaire, designed to help situate the sample and provide context for the final model. This also allowed interviews to be individualised, for example asking about friendships at work if the participant indicated they were in employment.

Medical information was gathered via the consultant (with participants' consent) to further situate the sample and enable consideration of study results in the context of participants' current HIV management (measured by medication adherence, CD4 count and viral load).

All participants identified their sexuality as heterosexual. Clinicians rated eight participants as showing 'good' adherence to medication (90% or more doses taken), and one (participant 2) as showing 'patchy' adherence (50 – 90% of doses taken). All other demographic and medical data is presented in Table 1.

Table 1
Participant Characteristics

<u>ID</u>	<u>Gender</u>	<u>Age (years): Interview</u>	<u>Age (years): Paediatric disclosure</u>	<u>Country of Birth</u>	<u>Ethnicity</u>	<u>Housing</u>	<u>Occupation</u>	<u>Relationship status</u>	<u>Most recent CD4 count (cells /mm³)</u>	<u>Most recent viral load (IU/mL)</u>
1	M	21	6 / 7	UK	Black African	Shared housing Or With family	University Student	Single	881	<40
2	M	23	12	UK	Black African	With family	University Student	Single	482	412
3	F	21	10 / 11	UK	Black Caribbean	With family	University Student and Working part-time	In relationship (live separately)	579	<40
4	M	16	11	UK	Black African	With family	College Student	Single	323	6539
5	F	22	17	Nigeria	Black African	Alone	Working part-time	Single	873	<40
6	M	23	10	Uganda	Black African	Alone	University student	In relationship (live separately)	558	<40
7	F	21	15	Europe**	Black Other	With family	University Student	In relationship (live separately)	657	Undetec-table
8	M	18	16	UK	Black African	With family	College student	In relationship (live separately)	368	Undetec-table
9	F	18	12	Rwanda	Black African	With family	College Student	Single	835	<40

*self-reported by participants **specific country removed for confidentiality

Analysis

Transcription. All interviews were transcribed by the researcher as soon as possible, using a denaturalised approach (Oliver, Serovich & Mason, 2005). This approach involves verbatim transcription that represents the ‘substance’ of a conversation, but does not depict the minute detail of accents or involuntary utterances within speech. A denaturalised approach is recommended for use in Grounded Theory methodology, where investigation centres on the meaning of social experiences rather than the language used to communicate them (Oliver et al. 2005). Denaturalised transcripts have also been identified as an effective way of conveying a conversation whilst maintaining participant confidentiality in HIV research (Oliver et al., 2005).

Coding. Coding is the sequential analysis conducted in Grounded Theory methodology, which enables raw data to be categorised and incorporated in to a theoretical model (Charmaz, 2014). Completion of this step-by-step process ensures that each code has ‘earned’ its way in to the final theory (Charmaz, 2014). The codes assigned to the data are emergent and constructed by the researcher’s definition of what they believe the individual’s statements represent.

First stage: Initial coding. Initial coding provides an “analytic handle” (Charmaz, 2014, p. 4) from which to guide the study. The researcher examined every line of each transcript and labelled it with an initial code describing what the data might mean. Initial codes were written in the gerund (verbs with ‘-ing’ endings) to

capture the process or action, as directed in Grounded Theory methodology (Charmaz, 2014). The researcher adhered to the Grounded Theory principle (Charmaz, 2014) of remaining open at this stage to whatever was emerging from the data. The initial codes from each transcript were compared and combined with each other, to ensure they were the best fit for the data.

Second stage: Focused coding. Focused coding exemplifies the interaction between researcher and data in Grounded Theory methodology (Charmaz, 2014). Focused coding involved comparing initial codes to clarify which made the most ‘analytic sense’ (Charmaz, 2014) and to identify emerging themes for potential inclusion in the model. The researcher labelled the most frequent or seemingly significant initial codes with a focused code which was more conceptual than the descriptive initial codes. This enabled the researcher to make potentially important phenomenon explicit (Charmaz, 2014) that were described but not directly named by participants, such as ‘anticipating stigma’. Focused coding enabled the researcher to identify gaps in the data to be addressed using theoretical sampling (the aforementioned efforts to recruit participants with experience of sharing their status with friends, when none of the early participants had done so).

Third stage: Theoretical coding. Theoretical coding involves connecting the focused codes to form the Grounded Theory. The researcher used memo writing (see below) to generate hypotheses about how the focused codes may be linked. Eight theoretical codes were created which integrated the focused codes and were

the final step between coding and creation of the final model. Charmaz (2014) highlights that it can be difficult for the researcher to discriminate whether hypothetical links between codes are truly being informed by the emerging data or whether this process is being influenced by prior knowledge. The researcher remained mindful of this during the theoretical coding stage.

Diagramming. Creating a diagram is the final stage of analysis in Grounded Theory methodology. It enables the researcher to illustrate the relationship between theoretical categories and highlight the direction of connections between them. A diagrammatic representation of the theory emerging from this study is presented in the results.

Memo writing. Writing memos is a key component of Grounded Theory methodology (Charmaz, 2014). The researcher wrote memos (Appendix 8) during the coding process to record their hypotheses about potential codes emerging from the data. Combining these memos with further collection and study of data enabled the researcher to refine emerging categories and supported the creation of focused and theoretical codes.

Reflective Diary. The researcher also kept a reflective diary (Charmaz, 2014) to record the process and experience of conducting the interviews (Appendix 9). Using this information aided coding, as it allowed the researcher to reflect on which topics had appeared particularly emotive for participants. Using the reflective diary

also helps the researcher to ensure they are interpreting the data, without using their own cultural, gender and other frames of reference to do so (Charmaz, 2014).

Research Quality

Six criteria for achieving a high standard of qualitative research have been proposed by Mays and Pope (2000).

The first is 'triangulation', whereby data from two or more sources can be compared to corroborate interpretations (Mays & Pope, 2000). The authors highlight however, that triangulation is a way of capturing more comprehensive data and should not be used on the assumption that a second data source will rectify weaknesses in the first (Mays & Pope, 2000).

'Respondent validation' is another quality assurance technique which involves comparing participants' feedback on the analysis to the researcher's interpretation (Mays & Pope, 2000). Both of these viewpoints should then be incorporated in the results.

Clear demonstration of the methodology involved in data collection and analysis is a third criteria for quality in qualitative research (Mays & Pope, 2000). The way in which initial data was developed in to themes should be transparent in the write up of the research (Mays & Pope, 2000), given the influence of this process on the final results.

Mays and Pope (2000) encourage the researcher to reflect on how the research process and also their own personal characteristics both influence the results. This is another criterion for ensuring the validity of qualitative research,

termed 'reflexivity'. The authors state that the researcher's personal and professional characteristics or biases should be detailed at the beginning of any reports. The differences between the researcher and the participant population should also be reflected on (Mays & Pope, 2000). The reflective diary used in Grounded Theory is one method for practising reflexivity.

'Attention to negative cases' is the fifth criterion, which ensures that research offers good quality explanations of the phenomenon being examined (Mays & Pope, 2000). Highlighting and addressing findings which appear to differ from or dispute the emerging theory (the 'negative cases') can develop and hone the analysis (Mays & Pope, 2000).

'Fair dealing' is the final criterion (Mays & Pope, 2000) for ensuring the quality of qualitative research. This states that research should encompass the opinions and experiences of a range of different participants, to ensure one perspective is not presented as the only valid position.

An evaluation of this study according to Mays and Pope's (2000) guidelines is provided in the discussion chapter.

Researcher Position

Conducting Grounded Theory involves an interaction between the researcher and the emerging data to 'co-create' the model (Charmaz, 2014). This interaction happens via the researcher's interpretation of what the data might mean, which is inextricably informed by their own culture, language and world-view (Charmaz, 2014). The researcher was therefore mindful that their own position was influential

in both the interview process and the interpretation of the data in this study.

Participants' choices about what information to share may have been influenced by the researcher being white British and conducting research with a population where this ethnicity was in the minority. Participants may have (correctly) assumed the researcher's HIV-negative status. This could have influenced how much they believed the researcher would understand their experiences. The researcher is a Trainee Clinical Psychologist with an interest in social constructionism and Systemic Therapy (Dallos & Draper, 2010). These approaches implicate problematic environments and societal narratives as causal in a person's experience of distress, rather than locating the problem in the individual. The researcher's occupation means they also hold values about the importance of emotional wellbeing and the reduction of distress. In this context, this translates to a belief that sharing one's HIV status with friends (provided the environment is safe to do so) would be a beneficial way for young people living with PAH to access support. It was important for the researcher to remain neutral during the interviews, to ensure the data collected did not reflect this position on disclosure. Participant's beliefs about mental health and what it means to engage with psychology-related appointments, even in a research capacity, may have influenced how much information they shared during the interviews. Further reflections on the researcher's position are detailed in the discussion chapter.

Chapter 3: Results

Summary

The analysis from interviews with nine young people living with PAH is presented. Eight theoretical codes were identified, constituting 25 focused codes that were formed from 77 initial codes (Table 2). Quotations are included to illustrate each focused code (identifying details removed).

Table 2
Table of Codes

<u>Theoretical Codes</u>	<u>Focused Codes</u>	<u>Initial Codes</u>
1. Influence of paediatric disclosure experience on friendships	1.1 Perceptions of HIV at time of paediatric disclosure	Not knowing what HIV was at time of paediatric disclosure Feeling shocked at being HIV-positive Feeling scared that being HIV-positive would result in death
	1.2 Feeling unable to share HIV status with anyone following paediatric disclosure	Feeling too overwhelmed to talk to friends at school about HIV Feeling unable to talk to friends due to not understanding the diagnosis Discovering HIV status at an important time for friendships
2. Influence of mother's HIV status on friendship decisions	2.1 Influence of mother being HIV-positive on sharing own HIV status	Being advised by mother not to share HIV status with anyone Making decisions about disclosure that go against mother's advice Considering mother's status when deciding whether to share own HIV status with friends
	2.2 Role of mother in managing HIV	Learning from mother's secrecy about her HIV status Receiving support from mother negates role for friends in providing this
3. Deciding whether or not to share HIV status with friends	3.1. Beliefs about needing support from friends to manage HIV	Feeling confident in ability to support self around living with HIV Not seeing any need to access support from friends
	3.2 Thinking about the disclosure process in advance	Playing out possible disclosure scenarios in mind Anticipating gender differences in reactions to disclosure Anticipating what the benefits of disclosure might be Recalling previous unexpected negative reactions to disclosure Considering risk of friend knowing HIV status if friendship breaks down Considering the possibility of romantic relationship with that friend

<u>Theoretical Codes</u>	<u>Focused Codes</u>	<u>Initial Codes</u>
	3.3 Anticipating discrimination in response to HIV status	Feeling scared that friends would treat the person differently if they knew their HIV status Hearing school friends making negative comments or jokes about HIV
	3.4 Establishing friend's possible reaction to disclosure	Testing friend's reaction to HIV-related discussions Observing friends' reactions to HIV related information Feeling certain of a best friend's views about HIV
	3.5 Experiencing distress around disclosure decision	Feeling afraid of sharing HIV status at all Wanting to share HIV status with friends, but feeling unable to Viewing sharing HIV status as too risky Worrying whether friends truly know each other if disclosure has not happened Feeling upset about having to lie to friends to conceal HIV status Feeling upset at thought of being defined solely by HIV status Feeling afraid of people making indirect disclosures Protecting self against distress with the decision not to share HIV status
4. Friendships with other people who do know HIV status	4.1 Sharing HIV status with friends increases support	Experiencing support with low mood after sharing HIV status Making part-disclosures to friends to increase support Finding it easier to talk to friends than medical professionals for support
	4.2 Support for managing HIV in intimate relationships	Receiving advice from friends about sharing HIV status with romantic partners Being reminded by friends about the need to practice safe sex
	4.3 Recognising other positive effects of sharing HIV status	Becoming closer friends as a result of sharing HIV status Feeling confident to subsequently share HIV status with others after a successful disclosure experience

<u>Theoretical Codes</u>	<u>Focused Codes</u>	<u>Initial Codes</u>
	4.4 Feeling surprised by reaction to sharing HIV status	Experiencing friend's reaction to sharing HIV status as less extreme than expected Expecting friends to mention HIV status again in the future, but they never do Trying to understand reasons for a friend's lack of reaction to sharing HIV status Encountering mother's reaction to decision about sharing own (young person's) HIV status
	4.5 Having to educate friends about HIV after sharing HIV status	Educating friends who assume HIV has been acquired sexually Noticing that people sympathise once they learn acquisition of HIV happened perinatally not behaviourally Recognising that sharing HIV status can educate people about managing PAH Consoling friends post-disclosure who think the young person is going to die from HIV
5. Friendships with other people who do not know HIV status	5.1 Receiving Support from friends even if they do not know HIV status	Having emotional support from friends for general (non-HIV related) issues Receiving emotional support for low mood without sharing HIV status
	5.2 Implementing Strategies to keep HIV status a secret from friends	Making choices that prevent friends discovering HIV status Avoiding discussion of personal topics when talking to friends Disguising HIV medication use around friends
	5.3 Friendships and HIV in the future	Feeling afraid of status being discovered in the future Identifying scenarios when sharing HIV status might feel possible in the future Wanting HIV and friendships to be different in the future Feeling ambivalent about sharing HIV status with friends in the future

<u>Theoretical Codes</u>	<u>Focused Codes</u>	<u>Initial Codes</u>
6. Friendships with other young people living with HIV	6.1 Differences between friendships with HIV-positive youth and other friendships	Keeping friends from HIV support group separate from other parts of life Finding it easier to build a friendships with other people also living with HIV Feeling more comfortable around friends at support group who are known to be HIV-positive Enjoying socialising at support group without actually needing to talk about HIV
	6.2 Valuing shared experience of being friends with other young people living with HIV	Finding it helpful to hear about the experience of other people living with HIV Getting tips about how to share HIV status from support group friends Getting support for medication adherence from support group friends
	6.3 Not wanting to make friends with other HIV-positive young people at support groups	Feeling at a different stage of living with HIV to other people at support group Finding it depressing to access support from HIV community for difficulties of living with HIV
7. Defining friendships	7.1 Identifying different categories of friendships	Categorising friendships based on the environment they were made in Having some friends who are only for fun Defining a best friend Difficulty establishing friendships within a big peer group
	7.2 Trust and friendships	Not wanting to keep secrets from friends Identifying trust and loyalty as the most important characteristics of a friend
8. Attitudes towards HIV	8.1 Personal attitude to privacy of HIV status	Wanting to be the only person who knows about HIV status Believing you would not share other health information with friends, so why share HIV status? Believing sharing HIV status is only necessary in sexual relationships, not friendships
	8.2 Personal adjustment to HIV	Feeling well adjusted to living with PAH

<u>Theoretical Code</u>	<u>Focused Code</u>	<u>Initial Code</u>
	8.3 Considering wider context of peoples' beliefs about HIV	Feeling that people do not know enough about HIV Recognising influence of stigma in continent of origin

1. Influence of Paediatric Disclosure Experience on Friendships

Eight participants recalled experiencing strong feelings of shock and fear at the time of paediatric disclosure. These feelings and a lack of understanding about HIV were cited as reasons why they did not share their HIV status with friends at that time. This decision appeared to have been compounded by paediatric disclosure happening when some participants were in a transitional period of their lives (starting secondary school), although there was a large range in the age of paediatric disclosure in this sample and these eight participants had not shared their status regardless of when paediatric disclosure had occurred. One participant (participant 8) did not report paediatric disclosure to be influential in their development of friendships, but they had been told their HIV status the most recently and had subsequently been able to share their status with friends. Two focused codes contributed to this theoretical code.

1.1 Perceptions of HIV at time of paediatric disclosure. Five participants described not knowing what HIV was, including not knowing about perinatal transmission of HIV, at the time of paediatric disclosure. Despite this lack of knowledge, participants still sensed that being HIV positive could be a distinguishing characteristic.

When you go to school they teach you about [how] people catch HIV and you try to think, no, it can't be! I'm totally different! I haven't done anything that they say, or other people do (participant-6)²

I still didn't really understand what [HIV] was, I just knew that I was a bit different to other people (participant-1)

Participants recalled how shocked they were at learning their HIV status. Even though they did not fully understand the diagnosis, this had been an upsetting moment for them and their most prominent thoughts were about the risk of dying at a young age.

That initial disclosure, like me finding out that I was... That was quite... That did take me out of it (participant-2)

She told me in like, the nicest way you can (...) that I was HIV positive and I remember just crying, even though I didn't even know what it was (participant-3)

² '...' indicates pauses during participants' speech, which were included in the transcript if the researcher felt this aided readers' understanding of the emotion being conveyed.
(...) indicates where a section of the extract has been removed for clarity.
Brackets indicate where details have been removed for anonymity: "When I went to (name of support group)"
Square brackets indicate where the researcher has added details to facilitate fluency: "I think that definitely would [be] weigh[ed] up"

You hear loads of facts but it doesn't mean anything (...) all I believed was what I heard about how many young people die from it (participant-7)

1.2 Feeling unable to share HIV status with anyone following paediatric

disclosure. Participants felt they had no choice but to keep their status a secret following paediatric disclosure. This was attributed to their lack of understanding about HIV; as well as feeling overwhelmed, isolated and unable to initiate a conversation about their HIV status. Some participants felt they had been told their status at a transitional time for their social world when they were starting secondary school. This appeared to influence how able those participants felt to make new friends or share their HIV status with friends at that time.

I didn't really plan to [tell anyone my status], 'cause for me it was such a new thing. I didn't really know much about it myself (participant-9)

I just kept that to myself. I didn't tell anybody. 'Cause for that moment you feel like you're different compared to the whole world and then you just think if I open... If I do say anything the whole world's gonna turn against me. That is how you feel. That's how I felt (participant-3)

I felt I was going to reinvent myself at that time, because I was going to secondary school. I thought do you know what, I'm just gonna be a bit relaxed. I'm not gonna be about school, I'm just gonna enjoy friends. But then this hit home... And I thought I can't... I can't be myself because no one is going to like me (participant-2)

2. Influence of Mother's HIV Status on Friendship Decisions

Two focused codes incorporated participants' descriptions of how having an HIV-positive mother had influenced their own friendships and management of the condition.

2.1 Influence of mother being HIV-positive on sharing own HIV status. Five participants had explicitly been told by their mothers not to disclose their (participant's own) HIV status to anyone. This had been experienced as a strong message, with participants describing that it was "*instilled*" in them (participants 1 & 4), or that their mother "*made me promise not to tell anyone*" (participant 7). Other participants had been more curious about their mother's advice not to disclose, but it had remained influential in their decision making. Three participants had gone against their mother's advice and shared their own HIV status with friends. One participant noted the complexities of living with HIV during adolescence.

I kind of thought oh maybe that's your insecurity and not mine. So I didn't really take too much notice of it, but it's something that I still remember (participant-4)

'Cause obviously my Mum wasn't born with it, I think growing up with it is a lot different to having like, contracted it later in life. So I thought (...) it would be better if I had someone know 'cause going through teenage years can be stressful enough like [without] adding that extra [stressor of keeping HIV status a secret]. So I thought like I would just tell [my friends] anyway (participant- 9)

Only three participants referred to their mother's HIV status featuring in their thoughts about sharing their own HIV status with their friends. Within that group there was a difference in perceived responsibility for revealing this information. Two participants acknowledged that their mother's HIV status was a factor, but not their main consideration. In contrast, one participant felt a moral obligation not to expose their mother as HIV-positive.

I hadn't thought of it in that way which is interesting (...) But then again if you say I've had it since birth, then it's like oh so your Mum has it, and... So... Yeah I think that definitely would [be] weigh[ed] up [in] the decision (participant-1)

I don't think I have the right to do that to her (participant-7)

2.2 Role of mother in managing HIV. Seven participants had experience of their mother's efforts to keep her HIV status a secret, either actively (disguising HIV medication with her) or as an observer (noticing who their mother told about her HIV status). In both these ways, their mother's secrecy around HIV status appeared to have influenced participants' feelings and choices about managing their own HIV status.

Even the medication, even disposing of the bottles, [in my family we are] kind of told to like just remove the labels (...) because someone could find out and that's what's been inbuilt I guess. It's just always... To keep it hidden
(participant-2)

I guess I didn't trust anyone to know. But, that I guess was kind of instilled in to me by my Mum. 'Cause like my Mum, although like some people know, like those are her close friends. Like, she wouldn't go around telling people. So, like, observing the way she acted (participant-4)

Having a mother living with the same condition was the reason four participants felt they did not need support from friends regarding HIV, even in the context of some of these participants having friends who did know their HIV status. These participants

were all still living with their mother though, which may have influenced their preference for, or the availability of, her support.

She's really good at being able to talk to about [HIV], (...) she will advise you if you, if it's something that you go to the clinic for or to the GP, and things like that. So she'll know if it's a HIV issue or not (participant-7)

I would probably go to my Mum rather than my friends, because my Mum knows about it (participant-9)

3. Deciding Whether or Not to Share HIV Status with Friends

The theme with the most data emerging from the interviews (five focused codes) was regarding participants' decisions about whether or not to share their HIV status with their friends. There was a lot of variability in how easy or difficult participants were finding these decisions, influenced by the participant's own adjustment to the condition, feelings of anticipated stigma and also their distress around the possible outcomes of sharing their HIV status. Thinking about the disclosure process in advance was reported by all participants.

Four participants had not disclosed their HIV status to any friends: three reported feeling too afraid (participants 1, 5 & 6), one believed it was not necessary (participant 4). Participant 2 had made an unplanned disclosure of their HIV status to

a friend whilst drunk, but viewed this as a one off, stating “*you wouldn’t ever catch me do[ing] that again*”. All the other data from their interview described being too afraid to share their HIV status with friends. Participant 7 had made one unplanned disclosure of their HIV status to a friend (who was about to hear the participant’s HIV status in a medical setting) and had also experienced a guessed disclosure (a friend identified the participant’s medication as HIV-related), but felt there was no need to share their HIV status with any other friends. Participant 3 had told two friends they had medical needs, but not named this as PAH (referred to as ‘part-disclosure’ in this discussion). Two other participants (participants 8 & 9) had made planned disclosures, and described sharing their status with four to six friends each.

The three youngest participants aged 16 – 18 years old appeared to be experiencing the least difficulty managing PAH and disclosure in friendships. Two had made planned disclosures to several friends (participants 8 & 9) and the other believed there was simply no need to share their status with friends (participant 4).

3.1. Beliefs about needing support from friends to manage HIV. Three participants who had not shared their HIV status with any friends described being confident in their independent approach to managing living with HIV; either because they had always coped alone or because they did not perceive any role for their friends in providing support. Other participants identified that their friends could be relied on for support, but still felt this was not necessary.

I'm so used to it (...) so I just use me all the way through (participant-6)

There is no point me telling them. What are they going to do for me? Nothing (participant-5)

[my friend] Would support me more, but I feel like I don't need that support... 'Cause I'm ok, I'm alright with it. If I did, then I would say 'look, I need help being told because I don't take my tablets'. I'd be honest. But I do [take my tablets] and it doesn't bother me, so I don't see why it should bother her (participant-3)

3.2 Thinking about the disclosure process in advance. All nine participants described various ways they thought about disclosure in advance (even if they had not subsequently shared their status or had only done so in an unplanned moment), indicating the importance of this decision for young people with PAH. Three participants had rehearsed possible disclosure scenarios in their mind, but had not carried these out. Two of those participants, and one other, were able to anticipate what the benefits of sharing their HIV status with a friend might be in abstract terms: *"there may be a better relationship [with that friend]"* (participant 4), *"[it would] take a bit of the burden off you"* (participant 6) and *"[I would] get it off my chest"* (participant 1). When they imagined more specific outcomes of sharing their status with friends though, participants only imagined a negative reaction, which could be

one reason the rehearsed disclosures never happened. The fear of saying the imagined conversation out loud may also prevent it from happening, despite such detailed rehearsal.

I'd like run scenarios through my head and it always turned out that people would just act like... They would accept to my face but... Maybe it just wouldn't be the same [after that] (participant-2)

Sometimes you practice in your head, you're like: I'll go to them, speak to them, bring up a topic about HIV, ask them what they think about someone with HIV, and ask them if they would be friends with someone HIV, and then tell them 'yeah look I'm HIV [positive], I've been on medication for a couple of years now'. And you know, that's how I would, you know, practice in my head. But [I've] just never put it out there (participant-6)

Participants also considered past and future events when thinking about sharing their HIV status with friends. Two female participants (participants 5 & 7) had negative experiences of sharing their status with a male sexual partner and the memory was reinforcing their decision not go through the disclosure process with friends. Three other participants had been thinking about the unpredictability of friendships in the future, specifically the resilience of trust within a friendship. Feeling worried about indirect disclosures if a friendship broke down was a barrier to

disclosure for some participants. Conversely, participant 8 acknowledged this risk but felt certain he could trust his friends.

There was this guy I was dating, and I wanted to be honest with him and I told him, but telling him, he went to tell all of his friends, you know... And so I just learned a lesson from there and so I'm never gonna tell nobody (participant-5)

Make sure you don't fall out with them in any way. Or know that you can trust them that if you did fall out, that they would keep that information to themselves (participant-8)

Finally, participants also thought about gender differences in relation to sharing their HIV status with friends. Participant 1 (male) held assumptions that sharing his status would be more difficult with a female friend because he believed she may raise the subject again in the future, which he may have wanted to avoid. Participant 9 (female) felt that it would be easier to disclose to a female friend, based on her belief that sharing personal information was normative for her gender. The two participants who had shared their status believed it was easier to tell a friend of the same gender, because those friendships were viewed as exempt from becoming sexual relationships in the future.

I feel that sometimes some guys are just like oh, ok, whatever... We'll move on. And sometimes... Some girls might hang on to it (participant-1)

I think just girls are like more open with every aspect of their lives (participant-9)

[disclosure] would feel different [depending on the gender of the friend]... Because, if I was to tell a female friend I'd be thinking that you never know what could happen [sexually] in the future (...) So like in that sense like my HIV could, like... It affects them. Since I know that I'm heterosexual, I know that my male friends wouldn't be affected at all (participant-8)

3.3 Anticipating discrimination in response to HIV status. Three participants believed they would experience discrimination if their friends learned their HIV status. They were afraid that friends would treat them differently, for example not sharing items with them, or that friends would avoid them once they knew their HIV status. Participant 9 highlighted the high perceived cost of disclosure, explaining that the friendship would be unsustainable if enacted stigma occurred.

The thought of [friends leaving me], that scares me. That terrifies me.

(participant-1)

If she reacted negatively I'd have to find like a new group of friends, 'cause I

don't think I'd be comfortable with her (participant-9)

Also contributing to anticipated stigma were participants' experiences of hearing people make discriminatory remarks about HIV. Three participants heard their friends making jokes or negative comments about HIV, which left them feeling uncomfortable.

Two of my friends that I talk to quite regularly, they were just jokingly talking about the condition and I was just there sort of awkwardly not saying anything (participant-1)

[people make] The most ignorant comments, and you're just there like... And it's ... your heart... I do remember my heart going [acts out heart bursting], like 'oh my god!' Any time someone said it (participant-3)

3.4 Establishing friend's possible reaction to disclosure. Three participants described trying to ascertain a friend's attitudes towards HIV, to inform decisions about who to share their status with. Participants observed friends' discussions

about HIV (participant 5), friends' reactions during biology lessons about HIV (participant 9) and friends' responses to portrayals of HIV in the media (participant 7). Participants 4 and 9 had also taken a more active approach by asking friends about several evocative topics and using those discussions to infer how they might react to her HIV-positive status.

Sometimes you know how they'd react by how they react to other things – like when [they see] someone has HIV on [television] and they're like 'Oh my gosh!' So then I'm like, well I'm never telling you then! [Laughs] (...) Then you see the ones who are like 'Oh that's so unfortunate', then that means that they must know a little bit about it (participant-7)

[I ask about] Other illnesses, even like sexuality as well, 'cause that can be like kind of thought provoking, like religion [too] (...) See if they are open minded and stuff. I think that's the main thing, like if you are open minded in other stuff then they'll probably be open minded with [HIV] (participant-9)

Participants did not, however, describe using this process with their best friends. There was a sense that participants were already certain their best friend did not hold prejudice views about HIV (pre-disclosure) and would respect the information about their HIV status (post-disclosure).

My best friend would never make a comment like that, she'd never! In the amount of years I've known her (number of years) she's never made a comment like that and she's had no idea [about my HIV status] (participant-3)

Since I told them I've got the HIV thing, they know that's a personal thing, they will never use it as a joke, never use it as banter (participant-8)

3.5 Experiencing distress around disclosure decision. Participants who had not shared their status with friends described feeling afraid to do so or not wanting to 'stand out'. Participants were also experiencing conflicting thoughts and emotions around the disclosure decision. Some participants believed their friends would react well, but still felt it was too risky to share their status with them. Other participants wanted to share their status with friends, but felt unable to do so.

It's always the worry that if I disclose I'm some sort of special, but in a negative way (participant-2)

Interviewer: So would you class [sharing] your status as one of those 'deepest fears' that you just mentioned (...)?

Participant: Yeah, yeah, my biggest fear (participant-3)

The thing is, I know that the friends that I have would be supportive. It's just...

I... No. I don't want to (participant-1)

Sometimes I feel in myself I should tell them. I should tell people. But then

again I get held back. I'm like no, I'll just leave it (participant-6)

A source of sadness and worry for two participants was believing that friends did not truly know them because they had not shared their HIV status. The strength of these feelings was revealed when they began crying whilst expressing these thoughts. One participant had attributed his entire evaluation of himself as a friend to this one factor.

Even though they know me, they don't... They don't maybe know the whole

me as it were (participant-1)

Because I didn't disclose who I was completely... I did feel like a false... A false

friend (participant-2)

These two participants were particularly upset by the lying involved in concealing their status from friends; either because it reminded them of their HIV-positive status or was something they regretted doing. One participant expressed seemingly contradictory beliefs; regretting that he had not been more open with friends in the past about his HIV status, but still feeling unable to share this with friends at the present time. One reason for this was that he did not want to be defined solely on the basis of his HIV status, which was a dislike also expressed by two other participants.

I guess that also... made [having HIV] a bit more real, that you had to lie, you had to physically like lie to people (participant-2)

I wish I could just rewind to being like here, I have [HIV]...right from the beginning... This is me... All out there (participant-1)

I like my friends knowing how I am without that (participant-1)

Another fear for participants was that if they told a friend their HIV status, they would lose control of this very personal information and indirect disclosures might occur. The advent of social media had increased this fear for participant 1. Understandably, three participants had concluded that not sharing their status was

the safest way to protect themselves from any distress. Participants who had shared their status, however, had not given any consideration to the risk of indirect disclosures, highlighting the variation in feelings of fear between those who had or had not shared their status with friends.

It did kind of move from worrying about how they'd treat me to just actually keeping it to themselves (...) I think that was more of a worry for me
(participant-2)

Nowadays you've got Twitter and Facebook and so on. It's like you're connected to so many people nowadays that if you told someone, someone knows someone, who knows someone who... And so, like it's worse to control
(participant-1)

You know, that fear of being rejected also just comes with [disclosure]. So just to avoid, you know, everything, you just [do] not say anything at all
(participant-6)

I've never actually thought like what would I do if someone did tell (...) But I guess I wouldn't be too bothered (participant-9)

4. Friendships with Other People who Do Know HIV Status

Participants who had shared their HIV status with friends reported experiencing the benefits of emotional and instrumental social support post-disclosure. They also highlighted other post-disclosure outcomes, particularly feeling surprised that their friends had not reacted negatively. Five focused codes constitute this theoretical code.

4.1 Disclosing to friends increases support. The two participants who had shared their status subsequently accessed support from those friends when experiencing low mood; related to being HIV-positive or as a side effect of their ART. Participant 3 appeared satisfied that the 'part-disclosures' she had made were sufficient to elicit support for living with HIV too. Following the guessed disclosure, participant 7 appreciated that her HIV status did not dominate the support her friends offered.

I was feeling pretty down about [being HIV-positive] at the time, so I just told my friends about it and like what I was experiencing at the time, and they were there to kind of help me, guide me through it and say like it's alright (participant-8)

I was having problems with my medicines, they were causing really negative side effects. So yeah, I told [my friend] and she took care of me (participant-9)

I told [my friend] that I'm going through something that's very different and it's got to do with my health, and so she supports me with that (participant-3)

She knows how to be a friend and not always put that disease on your forehead, like whenever you have an issue with your partner, she will give you information like as a woman to woman (participant-7)

Two participants found it easier to talk to their friends than medical professionals about living with HIV. Participants had either shared their status with friends to access an additional source of support which may have been easier to relate to, or had been seeking a more personal source of support than they had experienced from medical services.

I felt like I'd only really talked to my parents and the hospital about it... And there wasn't really someone my age that I could like discuss it with (participant-8)

[medical professionals] make it seem like oh 'you're not being safe' and 'we should be concerned about you as a file' (participant-7)

4.2 Support for managing HIV in intimate relationships. The other post-disclosure support participants accessed from friends was regarding intimate relationships. Female participants sought advice when they were considering sharing their HIV status with their boyfriends. Both male and female participants had also been reminded by friends about the need to use condoms. This advice was reported to be particularly helpful for participants whose self-image did not revolve around their HIV status and was appreciated by participants if it was conveyed with a degree of trust by the friend.

When I was like 'oh I wanna tell my partner about this thing [living with HIV] that I'm going through', they would be like 'yeah it's fine' (participant-3)

With my friend, she knows I'm being safe and she will ask me [laughs] like 'do you want more condoms or something?' Like she'll say it like that, but she won't make it seem like I have to be told about the crime status [around HIV transmission] (participant-7)

I sometimes even forget that I have [HIV], so it's good to have someone there reminding me that I'm in that position and need to be responsible with what I do. So [my friend] he's kind of like my safety net in a way saying that 'don't go too wild, like you need to remember what you have and remember that you need to be responsible' (participant-8)

4.3 Recognising positive effects of disclosure. Two participants felt they had become closer to their friend after sharing their HIV status with them. This change was attributed to the effect of sharing information with the friend that they had never told anyone before.

We definitely became closer after that, we became best friends (...) I think [my HIV status] was my one biggest thing that nobody knew about, so now that was out I could tell her anything and yeah we were both there for each other
(participant-9)

Two other participants felt that telling one friend their HIV status had increased their confidence to disclose to more friends and also to partners.

When [my partner] asked me [why I took medication], I was like ok [I'll tell you], because I'd told (two friends) before, so it wasn't like I was scared
(participant-7)

4.4 Feeling surprised by reaction to sharing HIV status. Participants expected that sharing their HIV status would elicit a shocked reaction from friends. Participants were therefore surprised by their friends' seemingly neutral reaction to

them sharing their HIV status. The period after sharing their HIV status also proceeded more smoothly than three participants had expected. Participants had assumed that their friendships would change (for the worse) or that the information about their HIV status would be revisited, but neither of these predicted outcomes occurred.

It was nothing that I had anticipated. Like all that time ago, thinking about what could happen, I never thought someone would just go like 'ok'. Just an acknowledgement... You would think that someone would have some response like 'oh my gosh' or (...) Like someone would be as shocked as... Or it would be as hard hitting as [when] I heard it all those times ago (participant-2)

It got to the point where I had to say 'have you heard what I've just said?' (participant-3)

It kinda just went under the wrap... Like she just knew and carried [on], and we carried on with life (participant-9)

Participants had tried to understand their friends' neutral reaction to them sharing their HIV status. One participant wondered whether their friend viewed 'being HIV-

positive' as less prominent in someone's identity than they felt it was themselves.

Other participants attributed this neutral reaction to the nature of the friendship;

either that it had been long-standing enough to withstand the disclosure or that

friends did not hold the stigmatising beliefs about HIV that the participant suspected they might.

Maybe that's how [sharing my HIV status is] always gonna be (...) It's never gonna be a bang, it's just gonna be like 'oh right ok'. Like, that it doesn't matter, that it's irrelevant, that it's just a fact about me which, which doesn't change anything (participant-2)

[sharing my status is] Kind of like an eye opener of who I'm surrounded by and I'm realising that I'm not surrounded by people like that [who have stigmatising views about HIV] where I thought I was (participant-3)

I'm like oh maybe, maybe this is why our friendship is still together once I've told them, because we've been friends for a long time and because I know what kind of person she is (participant-7)

In contrast to their friends' neutral reactions, two participants encountered concern or anger from their mothers (or both parents) about sharing their HIV status. Their

mother's reaction did not prevent participants from going on to share their HIV status with more friends though.

[my parents said] Why did I tell [my friend]?! Because now she knows something that she could say to your other students! [I] was like well she's my friend, I don't see anything wrong (participant-7)

[my Mum] was quite surprised, and she was quite worried for me I guess. But she didn't react too well (participant-9)

4.5 Having to educate friends about HIV after sharing HIV status. When they shared their HIV status, several participants encountered assumptions from friends that the virus had been acquired through unprotected sexual activity. This required the participant to explain PAH to their friends as part of the disclosure conversation. Participants felt that explaining about PAH changed their friend's perceptions of their HIV diagnosis to a more sympathetic one.

A lot of people are uneducated and they don't know like, you can have [HIV] from birth. They think it's just through sex and [that] kind of stuff, and so yeah I definitely do include that, and they do get quite surprised (...) all of

them have been surprised. Like, 'oh you've had it from birth I didn't know that was possible!' (participant-9)

When I told my friends, the first thing they asked me was like 'ok, where [and] what did you do to get this?' So like, I think most people's like conceptions are that HIV can only be passed through sexual intercourse (participant-8)

When you tell people that you got it from your parents they suddenly sympathise with you, as opposed to if you say you got it from someone else. Then it's like 'oh you should have been protecting yourself' and things like that. [With PAH] it's just like, 'oh you didn't get a chance to do anything about it?' And like you just got it, there's nothing you could do, you [were] just born with it (participant-7)

Some participants perceived the opportunity to provide accurate information about HIV as a constructive outcome of sharing their status. They referred to “*re-educating*” (participant 8) friends about the differences between HIV and other sexually transmitted diseases, or correcting assumptions about HIV mortality. Two participants found they had to console friends post-disclosure who had misconceptions about HIV mortality.

So then [my friend], she carried on and learned something about [HIV] [rather] than the whole fear factor of it, and she saw oh people can actually live with it for a long time (participant-7)

Due to like, misconceptions about HIV, most people think that it's a type of disease where you are probably gonna die from it. So one of my friends was really worried that I was going to die at the time [I told him], and it took me a while to explain to him that I'm not, I'm not going to die, I'm ok (participant-8)

5. Friendships with Other People who Do Not Know HIV Status

Three focused codes illustrate the theoretical code incorporating participants' friendships with people who do not know their HIV status. Participants described being able to access support from friends, despite not sharing their HIV status. These participants explained how they maintain the secrecy of their HIV status, as well as reflecting on the future of HIV and friendships.

5.1 Receiving Support from friends even if they don't know HIV status.

Three participants who had not shared their HIV status with friends (participants 2, 4 & 6) and one who had only made a 'part-disclosure' (participant 3), reported that they were still able to access emotional support within friendships. Participants specifically described being able to access support for experiences of low mood.

Accessing this support had secondary benefits for participants who felt it enabled them to establish a connection with friends and feel 'normal', despite not sharing their HIV status.

I haven't gone in to [my HIV status], but in general yeah, like we help each other out whenever there's like a problem, or something (...) It might just be like 'yeah I feel you man, I feel your pain'. It's just good for someone (...) just to be there, to understand (participant-4)

She says to me I don't have to tell he [what the medical needs are], but either way [I've] got [her] support and it's really weird because that is all I need (participant-3)

Even discussing how, how bad my life is, even that it's like it's a relief 'cause it's someone to talk to. Yeah just that... Apart from probably my status, it's just like you know, it makes you feel normal in a way like you belong in a group of friends (participant-2)

5.2 Implementing Strategies to keep HIV status a secret from friends.

Participants described disguising their HIV medication in the presence of friends whom they had not shared their status with. Efforts to conceal his HIV status had a

much greater influence on the life, and potentially wellbeing, of one participant. He reported avoiding discussions of any personal topics with friends, choosing education options in locations where people did not know him and also feeling he had to end friendships because he had not shared his status.

I use like (painkiller packaging) and change it (...) and I say 'ah I'm having a headache I need to take some (painkillers)'. Yeah, then they would never suspect (participant-5)

It was also a lot easier to deal with (...) my status and (...) juggling the friendships, because I chose to travel... I didn't want pick a college near me (participant-2)

For most of my friendships... Just to keep it safe I wouldn't really ... I was probably a cold... quite a cold... I didn't really share anything about myself (participant-2)

You just feel like maybe it's not worth keeping that friendship... You just... You just let it drift apart... And you don't maintain it (participant-2)

5.3 Friendships and HIV in the future. Some participants reported feeling afraid that their friends might discover their HIV status in the future, and consequently realise the participant had been concealing this information. Other participants who had not shared their status with friends to date could describe scenarios when this might happen in the future. Participants only identified examples where they would share their status through necessity though.

If you're found out to have it and you haven't told anyone, it's a lot harder to sort of run away from that (participant-1)

I think if I was sick, and my friends went to visit me, then maybe I would say something because they might hear it (participant-7)

Several participants expressed a hope that they might manage HIV and friendships differently in the future. One participant wanted to meet other people living with HIV, but could only imagine this happening through someone approaching them and did not express how they might actively seek that friendship. One other participant viewed friendships as increasingly important relationships in which sharing their HIV status may now feel possible.

Hopefully! [Laughs] I will see someone [HIV-positive to make friends with].

But since I've been diagnosed, I [have] never seen no one come up to me and say 'Oh I'm HIV-positive' (participant-5)

I don't think I'm there yet, but I feel that these friends are so much more important to me than they have been before. Like... I feel like I'm invested and I want to... I want to keep the friendships up (participant-2)

The most prominent feeling was ambivalence about disclosure to friends in the future though, even for those participants who had felt able to share their status with several friends already. Participants were experiencing competing emotions: the desire to share their status, but ongoing feelings of uncertainty about doing so. Some participants also felt specifically worried about sharing their status in the future with friends at university, believing there was more at stake with that decision than past disclosures.

I think maybe in the future... I don't know when I might tell them... But I still don't know if it will happen at all (participant-6)

All my other friends that don't know it's like, should I tell them? Do I feel comfortable telling them? Like, it would make life easier but is it the right

time, kind of thing? 'Cause I've always got those thoughts in the back of my mind when I'm having conversations with people (participant-9)

The friends you have in university, they say [those are] like your friends for life, so I have to be more careful with how I share that information (participant-8)

6. Friendships with Other Young People Living with HIV

Six participants spoke about their experiences of friendships with other young people living with HIV they had met at support groups (used here to describe both youth groups and residential camps for young people living with HIV). Three participants (participants 4, 6 & 9) perceived these friendships to be a valuable source of support and information, and easier than friendships with non HIV-positive peers. Conversely, participants 2 and 3 had initially found the friendships helpful, but stopped attending support groups because they felt too different from other young people there. Participant 7 described ending friendships at support groups for the same reason. Three participants (participants 1, 8 & 5) reported not having any friends who were also HIV positive.

6.1 Differences between friendships with HIV-positive youth and other friendships. Participants described how much easier they found it to build friendships with other people also living with HIV. There was a sense of freedom

from the burden of concealing their HIV status when around these friends.

Participants also valued the shared understanding this group had of each other's experiences.

It's almost like you're friends before you're friends, do you know what I mean? There's already something that binds you, some sort of like community that makes you already friends (participant-4)

(support groups) [were] just like a massive sleepover with all these people that were all the same as you and yeah we were definitely a lot closer [than other friendships]. We kept in contact for years (participant-9)

One participant met someone at a support group that he already knew (from elsewhere), but neither had shared their status with each other. This could have been an anxiety provoking situation, but knowing the other person was in the same situation appeared to be protective against any distress. This highlights the unique process of forming friendships within this population.

Participant: It was almost like I'm naked in front of someone. Like you've just almost been exposed, but if you're both naked it's like oh... We're both just, yeah... Do you know what I mean?

Interviewer: You're in the same position aren't you?

Participant: Yeah we're in the same position, so [we] kind of got on with it. So I think that kind of made us closer (participant-4)

Participants felt more comfortable in the company of friends at the support groups, than they did around other peers not living with HIV. Participants enjoyed discussing other topics within those friendships too, demonstrating that socialising did not always have to revolve around HIV at the support groups. They also described feeling less anxious about seeking advice from friends in that environment, compared to other friendships.

They were good friends, they were really good friends. I mean I was comfortable with them because my status wasn't an issue because everyone (...) had their own story to tell (participant-2)

It might just be like discussing careers and what you are going to do later on in life, or something like that. And it's just like helpful to be around other people in the same situation, discussing things that are like directly correlated to life, 'cause sometimes you don't wanna just talk about HIV all the time (participant-4)

I was actually more free to talk to them about my status 'cause I know they are just like me. They understand what I'm going through, what I'm doing, or what kind of medication I'm taking (participant-6)

Three participants (participants 2, 4 & 6) described keeping their friends from support groups separate from other parts of their lives, but appeared to be reassured by knowing those friends were available if needed.

When we're away [from the support group] it's like ah ok... Like, get on with normal life, but we both know each other, we're there for each other like if we need anything (participant-4)

6.2 Valuing shared experience of being friends with other young people

living with HIV. In addition to the benefits described in code 6.1, participants also reported that it was helpful to hear the specific experiences of friends also living with HIV. Tips for how to share your HIV status and medication management were described as particular areas which participants valued learning about. This also helped participants with a valuable realisation that other people were experiencing some of the same difficulties they were.

People [at the support group] had disclosed and said it felt like a weight off their shoulders and stuff (...) And so I obviously asked them for tips and like yeah, decided to tell someone (participant-9)

Even if I say I've missed my medication, they will give you advice and say 'oh maybe get this app, it will remind you' or 'do this to remind you', so [the friendship] was quite close (participant-6)

It's good to let people know, especially if they're going through it as well, what stage you are [at] with everything 'cause everyone else [has] either been through it or tryna do it, yeah. And it's nice to just express it (participant-3)

6.3 Not wanting to make friends with other HIV-positive young people at support groups. Several participants either did not want to make friends at support groups or stopped attending, consequently ending the friendships they made there. A concern expressed by participants was that other people might be at different stages of living with HIV than they were. They believed potential friends might be more focused on their HIV diagnosis, have been more open with sharing their HIV status or that other people may be more unwell than they were.

I've always been reluctant and hesitant [to attend support groups], just because even though I know they're people in the same boat... I don't know how comfortable they are with their condition, so they might have told everyone (participant-1)

I just didn't like it so in your face, 'cause... For me, obviously I have my own way of dealing with it and [attending support groups] made me feel more like... I was different. I'm not. And I didn't see myself as different. And so (...) I just stopped going (participant-3)

[being around people] Worse than you...It makes you scared of the disease that you have (participant-7)

Two participants either anticipated, or had experienced, that socialising at a support group can have detrimental effects for wellbeing. They felt that being reminded of their own difficulties or hearing other people's struggles would be a trigger for experiencing low mood.

I don't think I can bring myself to go there, because if I go there with my problems then I'll be down (participant-2)

*I did actually [make a friend at the support group]. But then, they were a bit...
Well... A bit... Depressing! (participant-7)*

7. Defining Friendships

Participants explained the different types of friendships they had and also the importance of trust in friendships, which contributed to two focused codes constituting the theoretical code: 'Defining Friendships'.

7.1 Identifying different categories of friendships. Participants characterised friendships from work settings as being different to those made in educational environments. Participants also identified a 'best friend' as being the closest friendship and someone they could rely on. Participants labelled some friends as being solely for fun activities. These perceptions about the nature of different friendships appeared to have implications for HIV disclosure and support.

Even though work will be a big part of your life, unless you see those friends outside of work and you go to places outside of work then I think, I don't really feel like they have a need to know [your HIV status] (participant-8)

They are kind of like my more entertainment friends like, go to parties with them and have fun with them, go to the cinema with them. But they're not

like friends I'd go to if I have a problem for like comforting kind of stuff
(participant-9)

I feel like (my best friend) understand[s] me more. You know, like when you
tell someone something they already knew what you are talking about, or
what you are trying to say (participant-6)

Participants also reflected on the difficulties of establishing close friendships within a large peer group. This may have made it harder for them to identify someone to share their status with, as neither had been able to tell their friends they were HIV-positive (except in a one-off event whilst drunk for participant 2).

In a way that can be annoying, 'cause it's like, I'm friends with everyone but
at the same time I'm friends with no-one (participant 4)

7.2 Trust and Friendships. Trust and loyalty were frequently described as the most important qualities in a friendship. Participants 8 and 9 also described not wanting to keep secrets from friends. In an action likely to be linked to this belief, both had shared their status with several friends.

Someone that like, keeps things confidential [is important] as well (...) It's just
the whole idea, like someone could steal £100 from you or £1 from you, but

it's (...) not you know, the impact of it, it's just the actual action and the level of respect that you've kind of broken (participant- 4)

'Cause [my friend] did know like all my other little secrets and it was just this one little one and so it was nice to have someone that knows everything (participant-9)

8. Attitudes towards HIV

Attitudes towards HIV held by the individual living with PAH and the wider global community were relevant to participants' friendship experiences, captured in the three focused codes below.

8.1 Personal attitude to privacy of HIV status. Three participants believed that their HIV status was a private piece of personal information. This belief was reflected in their behaviour, as none had shared their status with friends (or had only done so in a 'one-off'). Two of the participants supported their actions by labelling their HIV status as no different to other health information that people withhold from friends. Some participants also felt that sharing one's HIV status was only necessary in sexual relationships and not friendships.

I want this area, this aspect of my life [my HIV status]... I just prefer... The less people that know right now is the best option for me (participant-1)

'Cause if you had something else would you tell everybody that? That's what I think about it, like if I had gonorrhoea or something – would I tell my friends I had gonorrhoea? I don't know (participant-7)

I don't feel [your HIV status is] really something you would say anyways. Because there's HIV-positive and HIV-negative, and there's other blood names. No one doesn't really come out and say 'my blood name is this', do you know what I mean? So it's not really something that you would just say (participant-3)

I just thought only [a potential husband] should know [my HIV status], 'cause, they're who I might end up being sexually with (participant-3)

8.2 Personal adjustment to HIV. Adjustment to living with HIV may also affect how participants related to friends or shared their status with them. Two participants described being able to carry on with life without focussing on their HIV diagnosis and consequently had not shared their status with any friends. Another participant who had not shared their status with any friends attributed this to the

diagnosis being concealable. One participant who had shared their status did not view being HIV-positive as something important enough to need concealing.

'Cause at the end of the day, it's not... I mean it doesn't consume my every minute of my waking life. And I'm not sitting here thinking maaaaan, I've got HIV. Like, I forget that I have it most of the time (participant-4)

I still go out there, I put myself out there, I make new friends 'cause nothing on me says I'm HIV [positive] (participant-6)

'Cause I didn't really see the point of just like keeping it like to myself, 'cause it's not, it's nothing too serious (...) It's nothing that's that much of a problem. So I just told my friends (participant-8)

8.3 Considering wider context of people's beliefs about HIV. Six participants referred to the wider context of HIV in relation to their experiences of friendships as a young person living with PAH.

Well I just wish all people, like everyone, really had an idea of what HIV is. You know, like understand the whole situation of when someone has HIV that it's not something scary or something to be scared of (participant-6)

[my friend said] 'I don't even know people that would be so ignorant [about HIV] like that'. And I thought woah, woah! What world are you living in! 'Cause in my world I've met some people... (participant-3)

Two of the participants born in sub-Saharan Africa recognised the influence of HIV stigma around sexuality or transmission that they had witnessed there, on their current experiences. They were afraid people would avoid them upon learning their status and neither had told any friends they were HIV-positive.

When people [in Africa] say 'I've got HIV' all they think about is gay people. That's really the big problem, that whoever has HIV or AIDS is [assumed to be] a gay person. So (...) they say they can't associate with anyone with that (participant-6)

When I used to be in Africa people used to say 'oh if you have HIV you're not allowed to drink from the same cup, you're not allowed to stay in the same place, in the same room', you know, that mentality (...) So maybe if you tell them, say 'oh yeah she has HIV' [then they'll say] 'I don't want her to ever come near me, I don't ever want her to touch [me]', you know. I've tried to avoid all these things (participant-5)

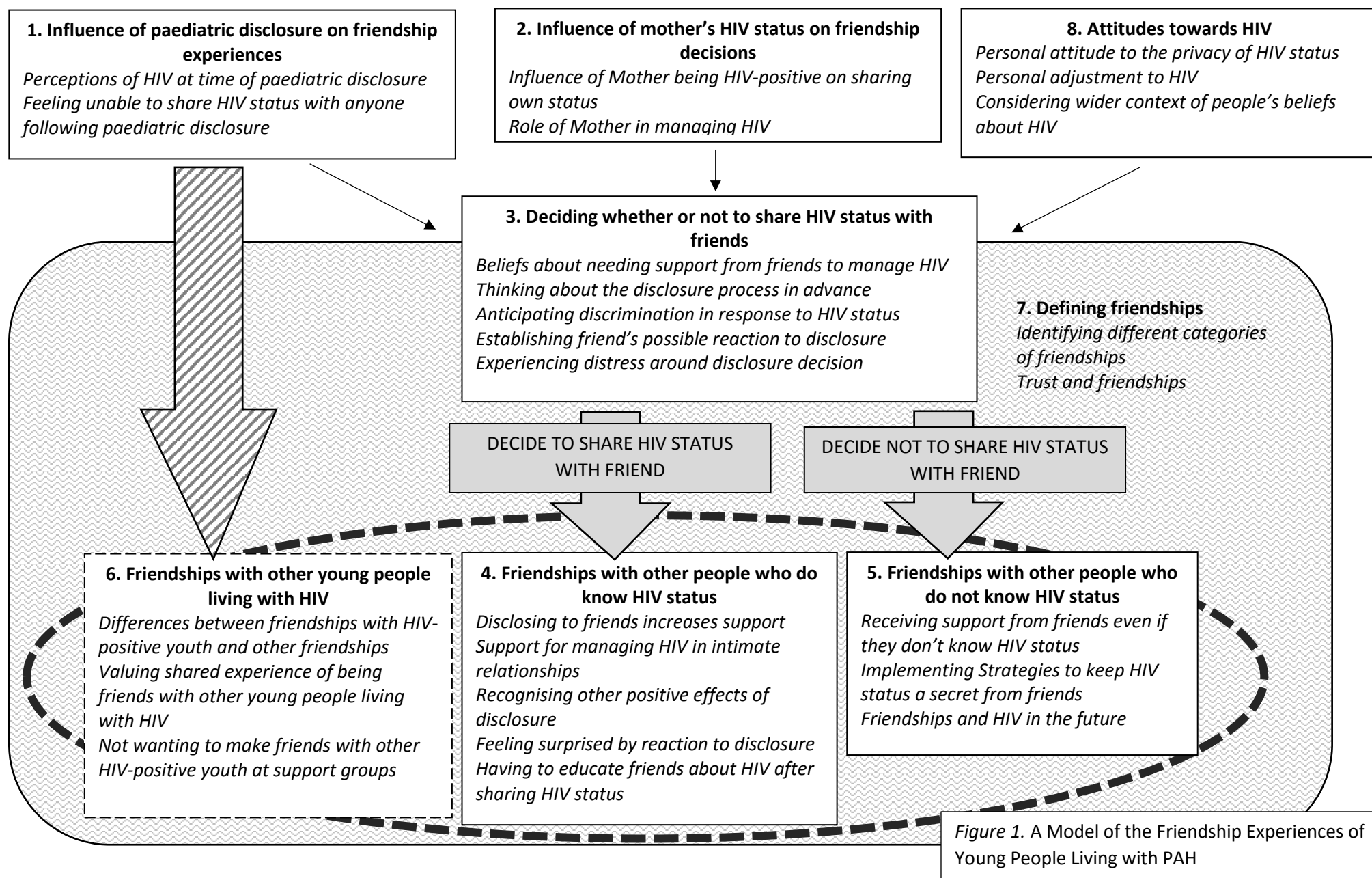
A Model of the Friendship Experiences of Young People Living with PAH

The aim of this study included developing a model of the friendship experiences of young people living with PAH. Figure 1 suggests how the eight theoretical codes emerging from the data could interact in an explanatory model of this phenomenon. The focused codes that form each theoretical code are included to illustrate the components of each stage.

The thin black arrows indicate that one theoretical code is influencing the other, in the direction shown. The paediatric disclosure experience, mother's HIV status and also attitudes towards HIV all are proposed to be influential in whether or not the young person living with PAH shares their status with friends. The thoughts and feelings subsequently involved in that decision are detailed within the code 'deciding whether or not to share HIV status with friends'.

The large grey arrows indicate the three possible pathways to friendships for young people living with PAH. The two solid arrows illustrate how the decision to share their status or not, consequently leads to friendships with people who do or do not know the young person's HIV status. The arrow filled with lines bypasses the disclosure decision, because paediatric disclosure (i.e. knowing you are HIV-positive) can lead to friendships with other young people at HIV support groups where disclosure is not necessary. 'Friendships with other young people living with HIV' appears with a dashed outline as it could be considered a subset of 'friendships with other people who do know HIV status', although the two have not been directly linked in the model as participants described keeping their friendships from support groups separate from other friendships.

The large dashed oval groups the three categories of friendships that young people with PAH might have and the experiences within each. 'Defining friendships' is shown by the patterned background to the model, as it is proposed to be influential to all of the codes it encompasses.



Chapter 4: Discussion

Summary

This aim of this study was to explore, and create a model of, the experience of friendships for young people living with PAH. Nine young people, aged 16 - 23 years old and living with PAH, were interviewed about their friendships to answer the following research questions:

What is the experience of developing friendships for young people living with PAH?

How does the HIV status of friends influence the friendships of young people living with PAH?

What are the perceived effects on friendships of having a mother who is HIV-positive, for young people living with PAH?

What factors are perceived to influence the decision of a young person living with PAH to disclose or not to disclose their HIV status to friends?

How do young people living with PAH experience sharing their HIV status with friends and how does sharing their HIV status or not subsequently affect the friendship?

Eight theoretical codes were identified and used to create a model representing the experience of friendships for young people living with PAH:

Influence of Paediatric disclosure experience on friendships

Influence of mother's HIV status on friendship decisions

Deciding whether or not to share HIV status with friends

Friendships with other people who do know HIV status

Friendships with other people who do not know HIV status

Friendships with other young people living with HIV

Defining friendships

Attitudes towards HIV

These codes will be discussed in relation to the five research questions, including consideration of how they relate to existing literature. Strengths and limitations of the study will also be presented. Personal reflections from the researcher, clinical implications for the findings of this study and directions for future research are outlined.

Research Questions

What is the Experience of Developing Friendships for Young People Living with PAH?

Defining friendships. The experience of developing friendships for young people with PAH involved categorising friends according to environment (work or school) or characteristics ('only for fun'). This system had consequences for which friends the young person considered sharing their status with and also which friends were viewed as a source of emotional support. The 'defining friendships' theme was therefore proposed in the final model to be influential to all the other codes.

Participants reported struggling to feel a connection with other people in large friendship groups. One explanation could be that these groups did not facilitate close friendships with other individuals, as theory suggests dyadic friendships may become more important than wider peer group acceptance during adolescence (Sullivan, 1953). Six participants did report having a best friend whom they felt particularly close to. This relationship may have benefits for participants' wellbeing, as feelings of closeness and security with a best friend have predicted

positive psychological adjustment in healthy adolescent populations (Demir & Urberg, 2004).

Trust and loyalty were named as the most important qualities of a friendship. Participants who had shared their status also described not wanting to keep secrets from their friends. Receiving a diagnosis of chronic illness can shift a person's internal values and cause them to appraise relationships differently (Rapkin & Schwartz, 2004). Although participants had been living with HIV since birth, they only 'received' this diagnosis at paediatric disclosure. These two friendship qualities may have become more important as participants subsequently faced decisions about sharing their HIV status in the context of anticipated stigma.

Influence of paediatric disclosure experience on friendships. In line with previous research (Dorrell & Katz, 2014), participants in this study recalled not understanding HIV at the time of paediatric disclosure. The timing of paediatric disclosure, lack of understanding, feelings of shock, fear and being overwhelmed by the experience were all influential in participants' development of friendships; as those participants did not share their HIV status with friends at that time.

Deciding not to share their status following paediatric disclosure could be regarded as the most influential point in the development of friendships for the PAH population. Particularly as participants did not share their HIV status with friends regardless of their age at paediatric disclosure, which ranged widely from 6 – 17 years old in this sample. This began the trajectory of concealing their HIV positive status and consequently one part of who they are from their friends. Four

participants in the current study never went on to share their status with friends and one other had only made a 'part-disclosure'. Participants had therefore been keeping their HIV status a secret for up to 10 years in some cases. Withholding information about the self can have detrimental effects for emotional wellbeing (Pennebaker, 1997) and several participants were tearful whilst discussing experiences of concealing their HIV status from friends.

How does the HIV status of friends influence the friendships of young people living with PAH?

Friendships with other young people living with HIV. There was a divide in how participants in this study felt about friendships with other HIV-positive youth. Some participants described finding it easier to make friends with other HIV-positive youth, compared to those who were HIV-negative. Participants explained they could talk more freely and felt more comfortable around friends who were in the same position as them (also HIV-positive). Findings from the PAH population in sub-Saharan Africa reported that children feel safer and more accepted around other children of the same status (Mupambireyi et al., 2014) and the present study suggests these feelings also continue into adolescence and early adulthood. These results also support existing literature indicating that young people with chronic health conditions find friendships easier with other people who have the same diagnosis (Kyngäs et al., 2008; Peterson et al., 2012). This ease has been attributed to the presence of an understanding about each other's situation (Kyngäs et al., 2008), which was also reported by participants in this study. Being able to talk about

other non-HIV-related topics with friends of the same status was also valued by participants. The same theme was identified in the friendship experiences of young people living with type 2 diabetes mellitus (Brouwer et al., 2012).

Some participants in this study identified friends who were HIV positive as a source of emotional and informational support, particularly learning from friends' experiences of sharing their status. Only one participant reported that HIV-positive friends gave support around medication adherence. Abramowitz et al. (2009) also found that young people living with HIV described receiving more emotional than instrumental support from friends. The authors highlight that this contradicts evidence from adult HIV populations, in which friends are often cited as a source of support for medication adherence (Abramowitz et al., 2009). Eight participants in this study were reported to have 'good' adherence to medication, whereas rates from the wider PAH population estimate only 50% of young people living with PAH are adherent to ART (Kim, Gerver, Fidler & Waud, 2014). Medication adherence may, therefore, not have been an area of difficulty which these participants needed support with.

Some participants reported that they found friendships with HIV-positive youth to be unhelpful, mainly because they felt very different from the other young people attending support groups. This contrasts existing theories of adolescent friendships within chronic health conditions suggesting the main difficulty is that young people feel different from healthy peers (Suris et al., 2004). One explanation for the result from this study may be the beliefs that participants had about HIV and their HIV status. The Self-Regulation Model (Leventhal, Nerenz & Steele, 1984)

outlines how persons' beliefs about their illness, termed 'illness representations', determine how they cope with it. One category of illness representations is 'identity', which incorporates a person's beliefs about the 'label' of the condition. Participants who appeared less distressed by their HIV-positive status, believed that making friends at support groups would place too much emphasis on the 'HIV-positive' label being part of their identity. 'Consequence' is another type of illness representation, which incorporates a person's beliefs about the effects an illness may have on social, physical and psychological functioning. Participants who had not shared their HIV status with anyone believed that potential friends at support groups might have been much more open with their HIV status. Participants may have felt that young people at support groups were less concerned by the social consequences of being HIV-positive than they were. Other participants felt it would be detrimental to their own wellbeing to be around people who were more unwell with HIV. This may also be explained by the participants' illness representations about the consequences of HIV, if seeing those people challenged their beliefs about being able to remain well whilst living with HIV. There are parallel emotional responses to illness which accompany these representations (Leventhal et al., 1984), which could explain why participants stated it was 'depressing' to be around potential friends who were more unwell. Adolescents with chronic health conditions such as diabetes, asthma and epilepsy have also reported believing that making friends with someone who had many complications would cause them to feel depressed (Kyngäs, 2004).

Three participants in this study reported not having any HIV-positive friends. Chaudoir and Fisher (2010) explain that people who have a 'concealable stigmatised identity' can find it difficult to find others with the same status. There are, however, well established third-sector services in London where young people living with HIV can meet. These participants may therefore be experiencing other barriers to socialising with HIV-positive youth, such as 'identity' related illness representations (Leventhal et al., 1984) which mean they do not want to base their socialising around 'being HIV-positive'.

Finally, participants reported keeping friends from support groups separate from other parts of their life. Fear of their HIV status being exposed (and the associated anticipated stigma) is one possible explanation for this strategy. Research has also identified how young people living with HIV create 'safe' social spaces where they can avoid stigma (Fielden, Chapman & Cadell, 2010). Spaces are 'safe' if they include other HIV-positive young people, or if they are somewhere the young person is able to blend in with peers who are HIV-negative. These two types of safe social space may represent the peer groups that young people in this study had established.

What are the perceived effects on friendships of having a mother who is HIV-positive, for young people living with PAH?

Influence of mother being HIV-positive on sharing own status. Participants valued their Mothers as a source of informational and emotional support for living with HIV, which negated any potential role for friends in providing this support. This

reflects the unique circumstances of PAH youth having a family member with the same condition, as young people with type 1 diabetes reported the opposite; they perceived support from friends more positively than support from parents (Carroll & Marrero, 2006). This finding may be different for the PAH population in sub-Saharan Africa though, where there is a higher number of HIV orphans than in the UK (Joint United Nations Programme on HIV/AIDS, 2010).

Participants' mothers' secrecy regarding their own HIV status (disguising medication use and not sharing her HIV status with friends) had direct effects for how participants managed their own HIV status with regard to friendships, as participants adopted these same strategies themselves. Their mother's management of HIV may also have had indirect effects. Sherman et al. (2000) state that family secrecy around HIV risks the HIV-positive child internalising shame about their own HIV status. If participants had experienced these feelings of shame, they are likely to be influential to their feelings about sharing their HIV status with friends.

Five participants had been told by their mother not to disclose their (participant's own) status to anyone, consistent with evidence that mothers frequently advise adolescents with PAH not to reveal this information (Michaud et al., 2009). The three youngest participants decided to share their status with friends anyway; citing a belief that there was no reason not to do so. This may reflect the success of recent campaigns to normalise an HIV-positive status for children living with HIV. The Children's HIV Association (CHIVA) launched a residential camp seven years ago in the UK, for young people living with HIV. One of the aims of the camp is to increase confidence and self-esteem in the context of living with HIV (Lut &

Evangelini, 2015). Only three participants reported that inadvertently revealing their Mother as HIV-positive featured in their thoughts and feelings about sharing their own HIV status with friends. This aspect of the familial context of PAH did not appear as influential to participants in this study as the existing literature suggests (for example, Calabrese et al., 2012).

What factors are perceived to influence the decision of a young person living with PAH to disclose or not to disclose their HIV status to friends?

Chaudoir and Fisher's (2010) Disclosure Processes Model (DPM) illustrates the complexity of the decision to disclose a concealable and stigmatized identity. Participants in this study also reported many different factors involved in decision making about sharing their HIV status with friends.

Deciding whether or not to disclose HIV status to friends. Decision making has been described as a process involving cognitive and affective components (Vastfjall & Slovic, 2013). Both of these components featured in participants' decisions about sharing their HIV status with friends. Thinking about disclosure in advance was described by all participants, suggesting this cognitive component was one of the most prominent factors in their decision making. Participants reported rehearsing what they would say to friends, imagining the benefits of sharing their HIV status and anticipating how the friend might react. Despite going through that process, many participants did not go on to share their HIV status with friends. One explanation may be that they were only imagining negative reactions from friends

during these rehearsals, as the literature indicates that disclosure of HIV status is inhibited if the person fears rejection (Derlega et al., 2003). The fear of anticipated stigma, which also emerged as a focused code relevant to the disclosure decision for participants in this study, may also have been more powerful than the increased confidence or reassurance that the rehearsal was providing. Wiener and Battles (2006) suggest that adolescents are particularly sensitive to rejection by peers, which may further influence participants' decision making.

The emotional component of decision making around sharing HIV status with friends was revealed in some participants' distress regarding the decision. Participants' distress resulted from feeling they had to lie to conceal their HIV status and their interpretation that not sharing their HIV status meant their friends did not truly know them. Efforts to suppress a stigmatized part of one's identity may result in people becoming 'hyper-focused' on thoughts about their identity in general (Smart & Wenger, 1999). This could be why one participant had reached the conclusion of labelling themselves a 'fake friend'. It may also be why several participants were worried about being defined solely by their HIV status if they shared this information with their friends. Emotions have been described as particularly important in social decision making (situations where decision making behaviour is influenced by, and has an influence on, other people) (Van Kleef, De Dreu & Manstead, 2010). A person's HIV status is health related information, but sharing this status with friends is a social decision, which may be why the affective component of the decision appeared so powerful for some participants in this study.

Some participants' decision making was characterised by feeling too afraid to share their status with friends and the most commonly reported fear was that friends would tell other people their status. Beck, Emery and Greenberg's (1985) 'anxiety equation' could explain the experience of these participants. The equation proposes that levels of anxiety depend on the perceived probability of a threat occurring and the cost of it, as well as a person's perceived ability to cope and perceived rescue factors that are available. The authors explain that people experience high anxiety when they overestimate the probability of a threat happening and assign a high psychological cost to it (Beck et al., 1985). Participants may have been overestimating the probability of stigma, rejection, friendship break down, indirect disclosures, negative implications for romantic relationships or social isolation occurring post disclosure. Participants believed these outcomes would be very upsetting and appeared to be minimising their ability to cope, with several participants stating that they would not know how to handle friends' rejection. Participants also seemed unable to identify any rescue factors, for example believing they would have to find alternative friendships if the current friends reacted negatively to their HIV status. This resulted in high anxiety for participants around sharing their status with friends and consequently a decision not to do this. Other participants wanted to share their status and believed their friends would react well, but still perceived sharing their status as too much of a risk. The anxiety equation (Beck et al., 1985) also accounts for this situation. These participants maybe viewing the probability of the perceived threat (indirect disclosures) as very unlikely, but the

perceived cost they attribute to it (possible outcomes from disclosure outlined above) may be so high, that they are not willing to risk it occurring.

Another explanation could be drawn from the Lazarus and Folkman (1984) Model of Stress and Coping. The authors propose that an individual will make a primary appraisal, classifying the stressor either as: a threat which can cause harm, a challenge which will result in positive future outcomes, or a harm-loss in which the damage has already occurred. A concurrent secondary appraisal occurs in which the person considers how able they are to effectively cope with the stressor. Some participants appeared to have made a primary appraisal that sharing their HIV status with friends is a challenge which will result in positive outcomes, such as support or increased feelings of closeness to friends. Other participants appeared to have appraised the stressor as a threat which will cause harm, such as loss of friends or discrimination. Some participants had heard school friends making negative comments or jokes about HIV, which had left them feeling uncomfortable and may have contributed to this threat appraisal. Wright et al. (2007) highlight that the adolescent peer group are in a developmental phase of exploring their own opinions and values. This may coincide with potential new friends making discriminatory remarks about HIV without being aware of the young person's status (Wright et al., 2007). This increases anticipated stigma around sharing their status (Wright et al., 2007) for the young person living with PAH and is likely to have been influential in the development of friendships for participants. Stereotypical beliefs about gender norms also appeared to be influential in some participants' thinking about whom to

share their status with, hypothesising that female friends may want to discuss the information more than male friends.

Establishing a friend's possible reaction to disclosure was also an important factor in participants' decisions about disclosure. Participants described observing their friend's reaction to HIV related information and also testing the friend's beliefs about HIV through questioning. This supports the proposal in the DPM that some disclosure events may occur over a longer period of time, beginning with people 'testing the waters' (Chaudoir & Fisher, 2010). Asking questions about HIV to establish a person's reaction has also been reported by young people living with PAH as a technique for managing HIV disclosure in intimate relationships (Greenhalgh et al., 2016). Participants reported feeling confident of their best friends' non-stigmatising attitudes towards HIV. One explanation could be that the person would not have reached a best friend status if participants had noticed them expressing any stigmatising views early in the friendship.

Some participants who not shared their HIV status with friends believed they were protecting themselves from distress with this decision. Other participants who had not disclosed their status to friends reported feeling able to cope with living with HIV themselves, so did not see a role for friends in providing support. This may be attributed their good adjustment to living with HIV, as Moss-Morris' (2013) Model of Adjustment to Chronic Illness identifies 'a sense of control over disease management' as one indicator of successful adjustment. Participants who had decided to share their status may have held 'approach' goals for disclosure, as outlined in the DPM (Chaudoir & Fisher, 2010). These are goals in pursuit of positive

outcomes, such as feeling closer to friends or gaining support from friends (Chaudoir & Fisher, 2010), both of which were reported as outcomes of sharing their HIV status by participants in this study.

Attitudes towards HIV. Some participants' beliefs that one's HIV status is something to be kept completely private, or is health information that friends do not need to know, appeared to influence their decision not to share their HIV status with friends. The DPM (Chaudoir & Fisher, 2010) highlights 'depth of information' as an influential part of the disclosure decision. This is an individual's belief about how private the information being considered for disclosure is to them.

Some participants described indicators of being well adjusted to living with HIV (Moss-Morris, 2013) such as acceptance of the diagnosis and maintaining activity levels in the face of illness. Feeling well adjusted to living with HIV may also have been influential to participants' beliefs that there was no need to share their status with friends.

Some participants also felt there was no need to share their HIV status with friends because they believed it was something that only a sexual partner should know. One explanation also from the DPM (Chaudoir & Fisher, 2010) could be that participants may have safety or moral antecedent goals for sharing their HIV status with partners, which do not apply to decisions about disclosure to friends. Although this study highlights that these two disclosure scenarios are not unrelated, as participants who had previously experienced negative reactions from partners did not want to share their status with friends, whilst one of the positive effects of

sharing status with friends was reported to be increased confidence in disclosure to partners. Participants' beliefs about other people's attitudes to HIV also influenced their decision about disclosure. Recalling stigma in their continent of birth remained a barrier to disclosure for participants who had been born in sub-Saharan Africa. In general, participants believed people were not educated about HIV transmission or PAH and making decisions about disclosure in this context may have left participants feeling unable to share their status.

How do young people living with PAH experience sharing their HIV status with friends and how does sharing their HIV status or not subsequently affect the friendship?

Friendships with other people who do know HIV status. Participants reported that sharing their status or a part-disclosure of their status both increased their access to emotional support from friends for living with HIV, for example when feeling low. This is an example of the direct support activation detailed in Sensitive Interactions Theory (Barbee & Cunningham, 1995) in which people ask for help by detailing the specific problem they are facing. There was also a feeling that it was easier to talk to friends than medical professionals about living with HIV. Rao et al. (2007) suggest that adolescents may perceive their doctors as holding power and authority, consequently feeling unable to be honest with them about any difficulties managing HIV.

Sharing HIV status in romantic relationships was one specific scenario for which participants accessed support from friends. Some participants accessed

emotional support (seeking reassurance about sharing their status with a partner), and others received instrumental support, for example having friends whom they viewed as a 'safety net' for reminding them to use condoms. Adolescents with type 1 diabetes mellitus have similarly reported their friends to be a 'safety net' for managing their condition (Carroll & Marrero, 2006).

Regarding the experience of disclosure, several participants' mothers had reacted negatively to the young person sharing their (own) HIV status with friends. This contradicted the reaction of participants' friends, who did not respond with the shock, negativity or repeated revisiting of the information that participants had anticipated. Participants also reflected on how friendships appeared either unchanged by the disclosure, or had become closer. Having friends who continue to socialise with the young person post-disclosure has been associated with an increase in perceived levels of social support for the PAH population (Lee et al., 2015). Therefore, even if they did not go on to use the friendships for support with managing HIV, disclosure may have increased participants' beliefs that support was available if needed.

Another common experience for participants around disclosure was having to educate their friends about HIV afterwards, which was also identified in the DPM (Chaudoir et al., 2011) as one way in which HIV disclosure affects social context. Educating peers about the condition was one reason given by young people with type 2 diabetes mellitus for deciding to share their diagnosis (Brouwer et al., 2012), however it was only reported as a consequence of, not a reason for, sharing HIV status in this study. Participants also reported having to reassure friends that having

HIV did not mean they were going to die. This is likely to require young people to be well adjusted to their own diagnosis and no longer feeling afraid of this themselves, as many participants had experienced fears about HIV mortality at paediatric disclosure. Participants also had to explain to friends about the perinatal route of HIV transmission, as their friends assumed they had acquired HIV sexually. This supports the suggestion by Kang et al. (2008) that young people living with PAH may encounter incorrect beliefs about HIV.

Finally, having a positive experience of sharing HIV status with friends increased participants' confidence to share their status with both friends and partners in the future. This has similarly been reported in adult HIV populations (Peretti-Watel et al., 2006). Two participants had experienced negative reactions when sharing their HIV status with a partner, which understandably left them wary of sharing their HIV status with friends in the future. These findings are reflected in the feedback loop of the DPM (Chaudoir & Fisher, 2010) which explains that each disclosure decision contributes to an ongoing process in which people become more or less open with their HIV status over time.

Friendships with other people who do not know HIV status. Four of the nine participants in this study had not shared their HIV status with any friends. Participants' efforts to conceal their HIV status were reported to be having negative effects on their friendships. As well as day-to-day strategies such as disguising medication, some participants had made extensive efforts to keep their HIV status secret from friends, such as avoiding the discussion of personal topics all together or

ending friendships in which sharing their status did not feel possible. These strategies could have consequences for the psychological wellbeing of young people living with PAH, if their basic human need for relatedness (Ryan & Deci, 2000) is not being met. Women living with HIV in South Africa have reported 'self-imposed isolation' as a coping strategy for dealing with HIV related stigma (Lekganyane & du Plessis, 2012) and participants may also have felt this was the only way to cope with their thoughts and feelings of anticipated stigma.

Participants described however, that they were able to access emotional support from friends even if that person did not know their HIV status. Two participants had accessed support for low mood and two others described receiving validation from friends when experiencing other problems in their lives. One participant accessed support for a 'health condition' after making a part-disclosure. This is an example of the indirect support activation outlined in the Sensitive Interactions Theory (Barbee & Cunningham, 1995, see chapter 1). These findings collectively provide evidence that choosing not to share one's HIV status does not necessarily equate to a reduction in the support that young people living with PAH might receive from their friends.

Participants reflected on friendships and HIV in the future, with regard to decisions about disclosure. There was a degree of fear that friends might discover the participant's HIV status, and therefore also realise the participant had lied to conceal it. Some participants expressed a hope that they would disclose to friends in the future and could identify scenarios when this might happen. Participants appeared to be experiencing conflicting emotions around a desire to disclose, but

remaining too scared to do so. Festinger's (1957) Cognitive Dissonance Theory proposes that holding conflicting attitudes produces feelings of discomfort. People are motivated to reduce the discomfort through action oriented towards achieving internal consistency. This may explain participants' expression of hope to manage friendships differently in the future.

Evaluation of the Present Study

Evaluation according to quality guidelines for qualitative research. The guidelines for ensuring the quality of qualitative research outlined by Mays and Pope (2000) (see Methods chapter) provided one framework for evaluating the present study. One limitation of the present study was that ethical approval was not sought for obtaining 'respondent validation' from participants (Mays & Pope, 2000) which may have provided valuable additional information to clarify the results. A review paper of evaluative criteria for qualitative research (Cohen & Crabtree, 2008) notes, however, that obtaining feedback from participants can also happen informally during conversations between the researcher and participant. The researcher used reflections and summaries throughout the interview for this purpose, to clarify participants' statements or prompt for further information. 'Triangulation' is the other quality guideline for corroborating findings with data from a second source, but this method was not used in the present study.

Clear description of data collection and analysis (Mays & Pope, 2000) also improves the validity of qualitative research, as the methodology "unavoidably influences" (Mays & Pope, 2000, p.2) the results of study. A transcript extract with

initial and focused coding is included in Appendix 10 to illustrate the analysis process and ensure this validity criterion has been met. Appendix 11 also shows how data from each participant's interview contributed to each focused code, to further explain the analysis.

'Reflexivity' is another criterion suggested for ensuring the validity of qualitative research. This requires acknowledging how the researcher and the process of conducting the research might have influenced the data (Mays & Pope, 2000). Reflections on the researcher's personal position have been included in both the methodology and discussion sections of this report. The researcher also kept a reflective diary (Appendix 9), to ensure they remained sensitive to the influence of their own assumptions and personal characteristics. Situating the proposed Grounded Theory in the data also reduces the risk of the researcher's assumptions and preconceived ideas about the phenomenon under investigation influencing the analysis (Charmaz, 2014). This study included quotations from interviews and also participants' demographic information to 'situate' the final theory in the data.

Mays and Pope (2000) also highlight the importance of 'attention to negative cases'. This involves the researcher addressing any data that does not fit with the emerging theory, with the aim of refining and improving the final theory proposed in the results of the study. Meeting this quality criterion was achieved primarily through the use of memos in this study. Possible explanations for data and the links between new or different data from each interview were recorded concurrently to data collection. Examining data during the latter stages of the study from young people living with PAH who had shared their status with friends (once the

recruitment strategy was directed towards seeking this data) could be considered 'attention to negative cases'. Data from these interviews contradicted the initial hypotheses being formed (based on the experiences of the first four participants) about how difficult it was for young people living with PAH to manage HIV disclosure and friendships.

'Fair dealing' is the final quality criterion (Mays & Pope, 2000) which involves protecting against one view point being portrayed as the sole truth about a phenomenon, by ensuring that a range of perspectives are represented in the data. The nine participants in this study represented a range of ages and experiences (around sharing their HIV status with friends, age of paediatric disclosure and feelings towards living with HIV) to the extent that this criterion could be considered met. Theoretical sampling was also used, within the limits of recruiting from the small clinic population, to ensure 'fair dealing'.

Evaluation according to quality guidelines for Grounded Theory

methodology. Glaser (1978) outlined four criteria by which Grounded Theory research can be evaluated; 'Fit' (codes should emerge from the data to 'fit' the phenomenon being examined and not be selected from pre-existing theory), 'Work' (how much the emergent theory provides explanations, predictions and interpretations of the phenomenon), 'Relevance' (studies should be relevant to action in the area of investigation through elaborating on the central processes and problems it involves) and 'Modifiability' (the Grounded Theory should be adaptable if any new data emerges).

Charmaz (2014) proposes four additional criteria for evaluating Grounded Theory; 'Credibility' (the strength of the links between data gathered and claims made in the analysis), 'Originality' (the research needs to offer new insight and extend current ideas), 'Resonance' (codes should fully portray the lived experience being studied) and 'Usefulness' (how much the research 'sparks' future investigations and contributes to both knowledge and everyday life). Charmaz (2014) suggests that research which is strong in originality and credibility, will increase the resonance and usefulness of its results.

This study examined the unique friendship experiences of the PAH population. This elaborated existing research examining friendships in other chronic health conditions and literature combining the PAH and BAH populations; therefore meeting Glaser's (1978) criterion for relevance and Charmaz's (2014) criterion for originality. The recommendations for future research and clinical practice outlined in this discussion are further evidence that the relevance, as well as the usefulness criterion have been met. Using the constant comparison method of Grounded Theory meets the fit criterion, as examining the data in this way ensured that codes were emergent. The researcher's memo writing also contributed to the development of codes and ensured the fit criterion was met. Constant comparison and memo writing also facilitated meeting the work criterion, as these techniques contributed to establishing the final interpretation of the friendship experiences of the PAH population. Reviewing the codes, using the researcher's reflective diary and writing memos to incorporate new data in the latter stages of the study (the

experiences of participants who had shared their HIV status with friends) could be considered examples of the modifiability of this research.

The researcher's initial line by line coding of two interviews was reviewed by the academic supervisor and the feedback was discussed in supervision. A peer supervision group was also set up with other researchers using Grounded Theory, to clarify understanding of the methodology. The group was also used to compare ideas about possible initial and focussed codes for extracts of anonymised transcripts. Feedback on the clinical recommendations was obtained from the Consultant at one of the study site clinics. These processes all ensure the credibility of the research.

Finally, the interview schedule was reviewed by a service user from a third-sector organisation supporting young people living with HIV. This supports the resonance criterion being met, as questions asked during the interviews had been confirmed as an accurate way to capture the lived experience of the PAH population.

Two other key parts of Grounded Theory methodology are theoretical sampling and theoretical saturation (Charmaz, 2014). Theoretical sampling involves recruiting participants with the intention of obtaining data that will help elaborate any emerging categories. The small population and limited recruitment opportunities (the primary site clinic only occurred monthly) meant that sampling could not proceed entirely in this way for the present study. Discussions were held with the clinical team, however, about the need to recruit participants who had shared their HIV status with friends when this experience had not yet been captured in the data. The interview schedule was also reviewed and questions added based

on experiences reported in the early interviews. These are proposed as theoretical sampling strategies within the recruitment constraints of the study, as they were efforts intended to develop the properties of emerging codes.

Theoretical saturation (Charmaz, 2014) involves continuing the research until no new data is being found to elaborate the emerging codes. In reality, much Grounded Theory research is not exhaustive to the point of theoretical saturation, so Charmaz (2014) and other researchers (Dey, 1999) advise seeking ‘theoretical sufficiency’ instead. This is defined as developing codes to a sufficient extent that the relationships between them can be explored and conclusions drawn. Theoretical sufficiency could be considered achieved in the present study.

Strengths and Limitations

In addition to evaluating this study according to qualitative research guidelines, other strengths and limitations are reviewed.

Strengths. This study was, to the best of the author’s knowledge, the first to conduct Grounded Theory qualitative research in to the friendship and social support experiences of young people living with PAH. The novel contribution of this study can further the understanding of experiences of the PAH population, which is valuable for informing clinical work (discussed below). This study also adds to the existing quantitative research in this area, namely, the study by Abramowitz et al. (2009) which examined friendships of the PAH and BAH populations by comparing self-report measures of friendship quantity and quality.

The principle of generalisability has been defined as ‘theoretical transferability’ in the context of Grounded Theory research (Sandelowski, 2004). Theoretical transferability is the principle that Grounded Theory research should produce results which can be applied beyond the specific situation from which the theory was generated. Several results from this study correspond with findings from other populations of young people living with chronic health conditions. One strength of this study is that the final model could therefore be considered to have theoretical transferability.

Another strength of this study was that demographics of the final sample are similar to those of the wider PAH population. Data from a cohort study (CHIPS, 2015) of young people living with HIV in the UK indicate the population is 53% female and 50% were born in the UK or Ireland. The sample population in this study constituted five male and four female participants; five of whom were born in the UK, one was born in Europe and three in sub-Saharan Africa. In the cohort study (CHIPS, 2015), 78% of the population were of Black African ethnicity and seven participants in this study identified their ethnicity as Black African.

Finally, there was wide variation in the age of paediatric disclosure within the sample population for this study. Results showed, however, that participants reported the same thoughts, feelings and decisions around paediatric disclosure regardless of their age at the time. It is argued therefore that a strength of the final model is that the codes presented are representative of the PAH populations’ experience whenever paediatric disclosure occurred.

Limitations. One limitation arising from recruiting clinic attendees is that the sample may not be representative of the whole PAH population. Specifically, those who did not attend clinic never had the opportunity to participate. There may be distinct characteristics of this population as research indicates, for example, that HIV patients with higher levels of depression are more likely to miss their clinic appointments (Holzemer et al., 1999). The young people who did not attend clinic may be experiencing the most difficulties living with PAH and it is a limitation of this study that their experiences have not been incorporated. It may also have been helpful to include a measure of current wellbeing in this study. The data would further inform interpretation of the results, for example hypothesising about links between psychological wellbeing and the experience of friendships.

Similarly, some young people may not want to participate in research on friendships if this was a particular area of difficulty for them. The model produced in this study may, therefore, not include the more severe difficulties with friendships that some young people living with PAH experience.

During discussions about friendships with other people who are HIV-positive, the researcher did not clarify whether participants were referring to friends who had a diagnosis of PAH or had acquired HIV behaviourally (BAH). This additional information would have been helpful to further understand the friendships, for example whether the PAH or BAH status of an HIV-positive friend influenced the type of experiences that were shared or the advice that was sought.

Finally, it was necessary to include a wide age range in the inclusion criteria, to maximise recruitment within this small population. One limitation, however, was

that the friendship experiences of the oldest (23 years old) and youngest (16 years old) participants may differ on the basis of characteristics associated with their ages. Two of the oldest participants lived alone, for example, which may mean they relied on friends more than younger participants who still lived at home with family.

Personal Reflections of the Researcher

One reason I undertook this research is that I have seen first-hand the global context of HIV, during travels around sub-Saharan Africa in the last ten years. Upon reflection, however, I believe I was still naïve at the start of this study about ongoing levels of HIV stigma; even in a large and diverse city such as London. I was shocked by the power that anticipated stigma still has, to the degree that four participants felt unable to share their HIV status with friends. I had assumed that most participants would currently be accessing support from friends as result of sharing their HIV status. I often left interviews feeling a great sense of injustice and sadness that many participants had not felt this was possible. I reflected on how magnified these feelings might be for the participants themselves.

Conversely, it was good to hear that two participants had felt able to disclose their status to their friends. These were the youngest participants, which does provide some indication that perhaps attitudes towards HIV are changing in a way that makes sharing their HIV status seem more of a possibility.

I had travelled to the countries where two participants were from, but I did not reveal this information during the interviews. I wanted to prevent participants overestimating my level of insight in to their experiences and also ensure my

experience did not influence data collection. I wondered afterwards however, whether it may have been beneficial to establishing the researcher-participant relationship to reveal this information.

I consider myself fortunate that within my friendships, I have a group of school friends that I have known for over 15 years. I value those friendships immensely and feel confident in sharing personal experiences with them, to generate support if needed. Since conducting these interviews I have been reflecting on how different those friendships might feel if there was a secret about myself that I had been protecting for all that time.

I am only a few years older than some participants and several of them were also aspiring professionals, suggesting we may have had shared values and goals. However, as I am an HIV-negative person from a white-British family with no history of chronic illness, our experiences may still have been very different.

Participants may also have perceived me as more aligned with the medical professionals than themselves, given the interview took place in a clinical setting which is an environment that often places the perceived power with the professionals. Within the interviews, participants of both gender expressed a preference for talking to friends of the same gender about their experiences. Both of these factors could have influenced the type or amount of information that participants chose to share with me, as a female professional.

Research Implications

Future research could examine the experience of friendship pairs, in which a young person with PAH has shared their status with an HIV-negative friend.

Conducting interviews both together and separately with participants would enable the fears and anticipated stigma the HIV-positive young person may be experiencing to be directly compared and contrasted with the friend's report of what they were actually thinking or feeling. Participants' fears in this study about their friend reacting badly, or perceiving them differently, left them feeling that sharing their HIV status was too risky. This proposed study would provide evidence for the differences between expectations and reality of friends' reactions to disclosure. This would be valuable information for supporting the youth HIV population around disclosure.

A second option for future research could involve adding quantitative evidence to the model of friendships proposed in this study. Measures of wellbeing could be compared for those who had, or had not, shared their HIV status with their friends. Some participants in this study described feeling distressed by managing friendships in which they had not felt able to share their HIV status. Quantitative measures of quality of life, or specific measures of depression and anxiety symptoms, would help to understand how these factors might relate to the experiences highlighted in the model.

Future research comparing friendship experiences within the UK PAH population according to country of birth would also be valuable. Initial results from this study highlighted how HIV-stigma experiences in their country of origin were still affecting the friendship decisions of young people with PAH who now lived in the UK.

Clinical Implications

Paediatric disclosure was identified as a significant point for the friendship trajectory of young people living with PAH in this study. One recommendation is that guidelines on paediatric disclosure (WHO, 2011) increase the emphasis on ensuring young peoples' understanding of HIV, so they consequently feel more able to share their HIV status with friends at that time. Based on the experience of participants in this study, this could protect young people living with PAH from years of potentially distressing efforts to conceal their HIV status from friends.

WHO guidelines (2013) identify a need to further understand how health workers can support adolescents living with HIV around disclosure decisions. This study has highlighted the wide range of both positive and negative experiences that young people with PAH have around disclosure in friendships. A recommendation based on these results is that support for young people living with PAH should recognise the numerous influences and outcomes involved in disclosure decisions for the adolescent HIV population. This population would benefit from being supported through a balanced exploration of all these factors. Health workers should help young people living with HIV to identify, examine and evaluate the wide range of possibilities, risks and benefits of sharing their HIV status with friends. There also is evidence from this study that sharing their HIV status with friends increased the confidence of young people with PAH to share their HIV status with sexual partners. Supporting disclosure in friendships may be one mechanism by which health workers

can support adolescents around disclosure in intimate relationships, with potential secondary benefits for reducing onward HIV transmission.

CHIVA guidelines (2013) state that young people living with HIV should have regular reviews, to identify any psychological difficulties they may benefit from support with. Another recommendation from this study is that friendships should be explicitly enquired about during all of these review appointments. This would ensure that an opportunity was provided to explore, and offer support around, the experiences highlighted in this study.

There is a role for Clinical Psychologists in offering training to help clinical staff facilitate these conversations at the young person's review. Workshops could also be run for parents, to raise awareness of the challenges their children may be facing around living with PAH during adolescence. Topics could include support managing the young person's changing relationships between family and friends during this time, and helping parents feel comfortable with supporting adolescents to share their PAH status with friends.

There is a role for the Clinical Psychologist in directly working with young people living with PAH too. Based on the results of this study, therapeutic approaches focusing on addressing perceived barriers to sharing their HIV status with friends (such as Cognitive Behavioural Therapy [Beck, 1979]) or reducing their experience of dissonance around sharing their HIV status with friends (such as Acceptance and Commitment Therapy [Hayes, Luoma, Bond, Masuda & Lillis, 2006]) may be helpful.

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Appendices

Appendix 1: NHS Research Ethics Committee (REC) Favourable Ethical Opinion

Letter



NRES Committee London - Camden & Kings Cross

Room 001
Jarrow Business Centre
Rolling Mill Road
Jarrow
Tyne & Wear
NE32 3DT

Telephone: 0191 4283545

14 April 2015

Miss Sarah Mann
Doctorate in Clinical Psychology, Royal Holloway University
of London Egham Hill
Egham
TW20 0EX

Dear Miss Mann

Study title: A Model of the Friendship Experiences of Young People
Living with Perinatally Acquired HIV

REC reference:

Protocol number: n/a

IRAS project ID:

The Proportionate Review Sub-committee of the NRES Committee London - Camden & Kings Cross reviewed the above application on 14 April 2015.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Hayley Henderson, nrescommittee.london-camdenandkingscross@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion – Favourable Opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk> Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion”).

Summary of discussion at the meeting

Social or scientific value; scientific design and conduct of the study

Members discussed the participants who are to be offered the opportunity to do the interview straight after their clinic appointment. It was agreed that this option should be removed and they should be invited to attend for the interview at a later date.

In addition, the out of pocket expenses may need to be adjusted to allow for this.

You explained that in order to maintain confidentiality of a person's HIV status, paper communication was not used in this setting, therefore sending study documentation in advance is unfortunately not possible. For that reason it is necessary to share the information sheet in person at the potential participant's clinic appointment. At one of the two sites, reminder telephone calls would be made to patients prior to their appointment, so they have added in the option for a member of the clinical team to mention the research during that conversation. This would ensure that some potential participants are aware of information about the study in advance.

If upon receiving the information sheet, the potential participant indicates that they wish to take part and wish to do so that same day after their appointment, then they have added the suggestion that the research appointment would be scheduled for a minimum of one hour after the clinic appointment had ended. This break had been added in order to allow sufficient time for a potential participant to consider the information and their decision to participate in the research.

The appointment schedule for patients attending this clinic was infrequent, meaning it may be a number of months before they return for their next scheduled appointment. Therefore, offering the option of a same day appointment not only increases choice for the service user regarding their participation, but may in fact present the most convenient option for them. If a person did take part on the same day, but then changed their mind there was also the option to withdraw and have their data removed from the study too. The participant would have the Chief Investigator's contact number on the information sheet, so would be able to phone and request this. You confirmed that any participant, who did come back to the clinic on a separate day solely for the purpose of the research appointment, would be reimbursed their travel expenses.

The Committee was satisfied with your response.

The Committee agreed that clarification regarding who would be providing the information sheet was required as page 8 of the IRAS application documents *“the clinician will use a script provided by the Chief Investigator and share the information sheet included in this application”* but then later says *“the information sheet will be shared by the Chief Investigator rather than the clinician”*.

You confirmed that this had been amended so that the procedure would always be that the clinician introduces the study and was always the person sharing the information sheet with the potential participant. At the interview appointment, the Chief Investigator would still verbally review that information sheet with the participant before taking informed consent, to ensure the information had been understood and any questions had been answered before commencing.

The Committee was satisfied with your response.

The Committee was not clear why the participant's GP was not being notified of their patient's involvement in this study.

You explained that all HIV related care for these participants is managed at the hospital clinics where the research is taking place. Therefore the clinician there rather than the GP was considered the most relevant medical professional to inform about a person's participation. Additionally, the participant's GP may not know their HIV positive status so to maintain confidentiality; any information about participation in this study is being kept within the clinical team at the hospital.

The Committee was satisfied with your response.

Approved documents

The documents reviewed and approved were:

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [RHUL Professional Indemnity Policy]	1	01 August 2014
Interview schedules or topic guides for participants [Draft interview schedule, Version 1, 01.04.2015]	1	01 April 2015
Participant consent form [Consent Form, [...SITE NAME...], Version 1, 01.04.15]	1	01 April 2015
Participant consent form [Consent Form, [...SITE NAME...], Version 1, 01.04.15]	1	01 April 2015
Participant information sheet (PIS) [PIS, [...SITE NAME...], Version 2, 12.04.2015]	2	12 April 2015
Participant information sheet (PIS) [PIS, [...SITE NAME...], 12.04.15]	2	12 April 2015
REC Application Form [REC_Form_12042015]		12 April 2015
Referee's report or other scientific critique report [RHUL Research Sub Committee Approval, Version 1, 01.04.2015]	1	06 February 2015

Research protocol or project proposal [Study Protocol, Version 2, 12.04.15]	2	12 April 2015
Summary CV for Chief Investigator (CI) [Sarah Mann, Chief Investigator CV, 12.04.2015]	2	12 April 2015
Summary CV for supervisor (student research) [Dr Evangeli, Supervisor, CV, 01.04.2015]		

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

With the Committee’s best wishes for the success of this project.

Yours sincerely

pp 

Ms Heidi Chandler

Chair

Email: nrescommittee.london-camdenandkingscross@nhs.net

Enclosures: List of names and professions of members who took part in the review
“After ethical review – guidance for researchers” [\[SL-AR2\]](#)

Copy to: Royal Holloway University of London

[...SITE NAME...], R&D Department

NRES Committee London - Camden & Kings Cross

**Attendance at PRS Sub-Committee of the REC meeting on 14 April 2015
held via correspondence**

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Ms Heidi Chandler (Chair)	Research Co-ordinator	Yes	
Miss Jessica Hughes	Director, Corporate Public Policy	Yes	
Dr Andy Petros	Consultant Paediatric Intensivist	Yes	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Mrs Hayley Henderson	REC Manager

**Appendix 2: Royal Holloway University of London Psychology Department Ethical
Approval**

Ref: 2015/060R1 Ethics Form Approved

psychology.it.support@rhul.ac.uk

Tue 6/30/2015 11:01 AM

To:

najt006@rhul.ac.uk; Evangelii, Michael

Cc: PSY-EthicsAdmin@rhul.ac.uk; Zagefka, Hanna; Lock, Annette; uqjt005@rhul.ac.uk

Inbox

Application Details: View the form click [here](#) Revise the form click [here](#)

Applicant Name: **Sarah Mann**

Application title: **A Model of the Friendship Experiences of Young People
Living with Perinatally Acquired HIV**

Comments: Approved.

Appendix 3: Approval from Research and Development Departments of NHS sites

SITE 1:

PROJECT TITLE Friendships of youth with perinatally acquired HIV (Version 2)

REC Reference

[...SITE DETAILS...]

CSP Reference (if applicable) N/A

Sponsor [...SITE DETAILS...]

Principal Investigator (PI): [...SITE DETAILS...]

Notification of [...SITE DETAILS...] host site permission

Permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed and approved were those specified in the ethics approval letter dated 14/04/2015. The protocol version approved is version 2.0 dated 12/04/2015

This approval is subject to the receipt of the HRA acknowledgment letter and associated document/s for minor amendment 01-June 2015.

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, and NHS Trust policies. Permission is only granted for the activities for which a favourable opinion has been given by the REC. The permission may be invalidated in the event that the terms and conditions of any research contract or agreement change significantly and while the new contract/agreement is negotiated.

The research sponsor, the Chief Investigator, or the local Principal Investigator, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety. The [...SITE DETAILS...]. should be notified that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action. The [...SITE DETAILS...]. should be notified within the same time frame of notifying the REC.

All amendments to this study (including changes to the local research team) need to be submitted in accordance with the guidance on IRAS. In addition any changes to the status of a study should be notified [...SITE DETAILS...].

Please note that [...SITE DETAILS...] required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements.

Any intellectual property that is identified should be discussed with the [...SITE DETAILS...] prior to any disclosure of this information by publication or presentations to ensure that all rights are protected.

At study closure, the [...SITE DETAILS...] together with the approving ethics committee should be notified that the study is closed. Study findings should be disseminated as identified in the original ethics application (including participants where appropriate). Study files should be appropriately archived.

Please contact the [...SITE DETAILS...] if you require any further guidance or information on any matter mentioned above. We wish you every success in your research.

Yours sincerely,

[...SITE DETAILS...]

CC. Miss Sarah Mann- Chief Investigator

SITE 2:

Title: A Model of the Friendship Experiences of Young People Living with Perinatally Acquired HIV

In accordance with the Department of Health's Research Governance Framework for Health and Social Care, all research projects taking place within the Trust must receive a favourable opinion from an ethics committee and approval from the Department of Research and Development (R&D) prior to commencement.

- **R&D Approval Date:** 10/06/2015
- **Chief Investigator:** Miss Sarah Mann

NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation as listed in the ethics letter of favourable opinion letter dated 14/04/2015. I am pleased to inform you that we are approving the work to

[...SITE DETAILS...]

Appendix 4: NHS Research Ethics Committee (REC) Substantial Amendment

Approval



NRES Committee London - Camden & Kings Cross

Room 001
Jarrow Business Centre
Rolling Mill Road
Jarrow
Tyne & Wear
NE32 3DT
08 July 2015

Miss Sarah Mann
Doctorate in Clinical Psychology
Royal Holloway University of London
Egham Hill
Egham
TW20 0EX

Dear Miss Mann

Study title:	A Model of the Friendship Experiences of Young People Living with Perinatally Acquired HIV
REC reference:	
Amendment number:	Substantial Amendment 1
Amendment date:	17 June 2015
IRAS project ID:	

The above amendment was reviewed by the Sub-Committee in correspondence.

Summary of Amendment

The submission of this amendment was to increase the nominal amount a participant would receive to take part in the study.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Notice of Substantial Amendment (non-CTIMP)	Substantial Amendment 1	17 June 2015
Participant information sheet (PIS) [Patient Information Sheet [...SITE NAME...],	3, highlighted	17 June 2015
Participant information sheet (PIS) [Patient Information Sheet [...SITE NAME...],	3, highlighted	17 June 2015
Research protocol or project proposal	3, highlighted	17 June 2015

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Yours sincerely

Pp



Mrs Rosie Glazebrook Chair

E-mail: nrescommittee.london-camdenandkingscross@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: [...SITE NAME...],

NRES Committee London - Camden & Kings Cross

Attendance at Sub-Committee of the REC meeting via correspondence

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>
Mrs Rosie Glazebrook (Chair)	Consumer Marketing	Yes
Dr Andy Petros	Consultant Paediatric Intensivist	Yes

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Donna Bennett	REC Assistant

Appendix 5: Interview Schedule

Initial questions

Do you remember approximately how old you were when you found out you were HIV positive?

Can tell me a about a few of your most important friendships from that time?

(Then, asking about each friend in turn...)

- How long had you known _____ before finding out you were HIV positive?
- How did you meet them? (E.g. School, family, community etc.?)
- Does _____ know your HIV status?
- Are they HIV positive too?
- What were the reasons that you decided to tell/not to tell _____ your HIV status?
- Beforehand, how did you feel about telling _____ you are HIV positive?
- What was it like telling _____ your HIV status?
- How did it feel afterwards when you had told _____ about being HIV positive?
- Do you remember why you were friends with _____? For example did you have any similar interests?
- How did these friendships develop over time?
- And are you still friends with _____ now?
- If not, why not?

Can you tell me about a few of the most important friendships you have at the moment?

(Then, asking about each friend in turn...)

- How long have you known ____?
- How did you meet them? (E.g. School, college, clinic, work, etc. ?)
- How has this friendship developed over time?
- Does _____ know your HIV status?
- What were the reasons you decided to tell/not to tell _____ about your HIV status?
- Beforehand, how did you feel about telling _____ you are HIV positive?
- What was it like telling _____ your HIV status?
- How did it feel afterwards when you had told _____ about being HIV positive?
- Are they HIV positive too?
- Why are you friends with _____ ?

Intermediate questions

In your experience, how has living with HIV affected your friendships?

- *In what ways?*
- *Does having HIV affect how you make new friends?*
- *Does having HIV have any effect on your long term friendships?*

Thinking about your current friendships which you told me about at the beginning of the interview....

(Asking about each friend in turn, who was mentioned earlier....)

- *Are there any examples of when being HIV positive has been a good thing for that friendship, for example might sharing experiences bring you closer together?*
- *Are there any examples of when being HIV positive has not been good for that friendship, for example not being able to talk to friends about HIV?*

Can you tell me any ways in which friendships with other HIV positive people are similar or different from friendships with HIV negative people?

Are the thoughts and feelings we've been discussing, about telling other people your HIV status, different depending whether the other person is HIV positive or not? In what ways are they the same or different?

Would you consider your friends to be a source of support for living with HIV?

- *Can you give me any examples of the ways in which your friends do support you?*
- *For example, practical help with things? Providing information?, emotional support?*
- *Are there any other indirect ways that your friends support you? Or that you find friendships supportive?*
- *For example just having fun together? Sharing the same interests?*
- *Can you give me any examples of how you ask for support from friends?*
- *Are there any other way you might let them know you need support, without explicitly asking? (for example, dropping hints? Saying you feel unwell?)*
- *Is that different from the support you get from other sources like your family?*
- *Or medical professionals?*
- *Are there any more ways, or different ways, that you would like your friends to support you?*
- *Are there any reasons that you wouldn't want to ask your friends for support?*

Do you have any friendships which are also sexual relationships?

- *Are these friends also HIV positive?*

- *Are there any ways, apart from sexual activity, that these friendships are different to non-sexual friendships?*

Are you part of any bigger groups of friends too?

- *How do these groups differ from the individual friendships we have talked about?*
- *Do people in the bigger friendship groups know your HIV status?*
- *Are the people in these bigger friendship groups more or less important to you?*
- *Are they more or less helpful to you in living with PAH?*

Are you aware of anyone else in your family's HIV status?

- *Do those family members know your HIV status too?*
- *Is this discussed at home?*
- *Has being from a family where other members are HIV positive too had any effect on your friendships?*
- *Can you give me any examples of when this has happened?*

Ending questions

Is there anything else you think would be important for me to know about your experiences of PAH and friendships?

Questions added after initial interviews:

Do you think about friendships and HIV in the future?

- *and about how these might be the same or different to friendships now?*

Do you and your brother/sister talk to each other about living with HIV?

Appendix 6: Participant Information Sheet

[UNIVERSITY AND NHS TRUST LOGOS]

Participant Information Sheet: Research Study

Title: A Model of the Friendship Experiences of Young People living with Perinatally Acquired HIV

A study is taking place in this clinic exploring what friendships are like for young people who have Perinatally Acquired HIV (PAH). We would like to invite you to be interviewed by Sarah Mann, a Trainee Clinical Psychologist from Royal Holloway University of London, about your experiences of friendships and how having a diagnosis of PAH might affect those friendships.

The interview will last between 45 – 90 minutes. Before you decide if you want to take part, it's important that you understand why this study is being done and what will happen if you take part. Please read this sheet carefully. If you want to discuss the study with a member of clinic staff before making a decision about taking part, please feel free to do so. You can also ask Sarah Mann any questions you might have about the study.

Why are we doing this study?

We would like to find out more about what friendships are like for young people with PAH. We are particularly interested in people's experiences of making friendships and the different types of friendships they have. We are interested in how different friendships might provide support with managing PAH and the decisions people make around telling their friends about their HIV status. We are also interested in how growing up in a family affected by HIV might have affected the friendships of young people with PAH.

Why are you asking me to take part?

We are inviting you to take part in this study because you are a young person with Perinatally Acquired HIV and you attend this clinic where the study is taking place.

What will happen in the interview?

The interview will take place in a quiet and private room at this clinic. To allow you to be able to speak freely, we would ask that you attend the interview alone. Sarah will go through one consent form with you which confirms that you are agreeing to take part in the study. You can ask any questions you have at this point, before the interview starts. The interview will then take place, beginning with some questions about any current friendships you have, before talking more about how your friendships might have been affected by having PAH. The consent form also asks your permission for Sarah to access your medical records after the interview to

collect some basic information about your PAH, for example when you were told about your diagnosis.

Do I have to take part?

No, you don't. The study will not affect your care at this clinic in any way. If you decide to take part now you'll still be free to stop taking part at any time, without giving a reason. If you decide to withdraw from the study at any point your care will not be affected. You can let Sarah know if you want your data to be withdrawn from the study as well.

Will the interview be confidential?

The information from the interviews will be treated as highly confidential. Only you and Sarah will know that you have given the information you have. Her supervisor, Dr Michael Evangeli, Clinical Psychologist and Senior Lecturer, will have access to the information you give in the interview but this will be in an anonymous format.

The only exception to this is if you tell Sarah something during the interview that suggests that you or someone else might be at risk of serious harm (for example, if you tell her that you are planning on harming yourself or someone else). Sarah will need to speak to your clinical team about this, so that they are able to provide you with support. Sarah will let you know if this is going to be necessary.

What will happen with the information we collect?

The consent form, which you will be asked to sign if you decide to take part in the study, will be the only document that will have your name written on it. The consent form will be kept separately from the responses you provide, in locked filing cabinets at the clinic and destroyed 2 years after the study has ended.

The interviews will be recorded on a Dictaphone before being transcribed and stored as word documents in password protected computer folders. The recordings on the Dictaphone will be deleted once they have been transcribed.

These word documents will be anonymous and labelled only with a code for each person. The same code will also be written on the consent form, linking the two together. This is so that if you decide to withdraw your consent after the interview has taken place, we will be able to locate your answers.

Who will be writing up the research?

Sarah will look at the information from this study carefully and use it to write a thesis as part of a professional qualification to become a Clinical Psychologist. We hope that these findings will be used to plan health services for the future too.

Before the thesis is written, you will have an opportunity to hear about the main themes from the study and give feedback on these if you wish to. You can contact Sarah on the phone number below between [...DATES...] and she will get back to you

to discuss this over the telephone. If you don't wish to have any further involvement after the interview, there is no need to do so though.

The data collected may also be used to write academic papers for publication or may be presented at conferences. No identifiable information will be included in these papers or the conference presentations.

Are there any disadvantages or risks of taking part?

Some people might find talking about HIV difficult, sensitive or in some cases upsetting. The questions will be asked in a sensitive way during the interview and you don't have to answer any question that you don't want to. The questions do not have a right or wrong answer, we are interested in hearing about your experiences. If the interview does affect you in any way please let Sarah know so that we can arrange for a member of your clinical team to help you with this.

Are there benefits of taking part?

You may find talking about your experiences helpful. The information you provide will help to increase knowledge about the experiences of young people with PAH. This knowledge could help to develop better services and provide information about how best to support other young people who have PAH in the future.

Will I get anything personally for taking part?

You will be compensated for the time you have given to take part in the interview, to the value of £15 in high street vouchers. If you come back to complete the interview on another day that you would not usually be attending the clinic, you will also be compensated for your travel expenses.

Who is organising the research?

The study is being organised by Royal Holloway, University of London. Sarah is completing the study as part of her professional qualification to become a Clinical Psychologist.

Who has reviewed the study?

Studies being conducted in the NHS are looked at by an independent group called a Research Ethics Committee. This study has been reviewed and given favourable opinion by a London Research Ethics Committee. This means the Committee is satisfied that your rights will be respected, any risks have been reduced to a minimum and that you have enough information to decide whether to take part or not.

What if I feel unhappy with the interview or the way I am treated?

If you are unhappy with anything to do with the research, please contact Sarah on the number provided below. If you are still unhappy, or you do not wish to talk to Sarah about it, please contact The Patient Advice and Liaison Service (PALS) at

[...*NAME OF HOSPITAL*...] who will be happy to listen to you and will help you make a formal complaint. Their number is [...*CONTACT TELEPHONE NUMBER*...]

What happens next?

If you would like to meet with Sarah to find out more about taking part in this research please let Dr [...*NAME*...] or Dr [...*NAME*...] your clinic Doctors, know. On some days, Sarah will be at this clinic and can meet with you in person to arrange a date and time for the interview. There is an option to complete the interview today if this is more convenient for you. If you chose to do this, Sarah would give you some time (one hour) to read the information and confirm your decision to take part, before meeting to do the interview. If Sarah is not in the clinic today, please call the number below and leave a message saying that you are interested in taking part in the study. If you also leave your contact details in that message, she will get back to you to arrange an appointment.

Thank you for taking the time to read this information sheet.

Sarah Mann, Trainee Clinical Psychologist [...*CONTACT TELEPHONE NUMBER*...]
[...*CONTACT ADDRESS*...]

Supervised by: Dr Michael Evangeli, Clinical Psychologist and Senior Lecturer
[...*NAME*..] Consultant Physician

Appendix 7: Participant Consent Form

[UNIVERSITY AND NHS TRUST LOGOS]

Participant Consent Form

Title of the Study: A Model of the Friendship Experiences of Young People with Perinatally Acquired HIV

Please

Initial

Name of Researcher: Sarah Mann

Ethics Committee Reference number:

1. I confirm that I have read and understood the information sheet dated..... (version.....) for the above study and have had the opportunity to ask questions which have been answered satisfactorily

☐

2. I understand that my participation is voluntary and I can withdraw from the study at any time, without giving any reason, and without my medical care and legal rights being affected

☐

3. I agree to have my interviews with Sarah Mann, Trainee Clinical Psychologist audio recorded

☐

4. I agree to take part in the above study

☐

5. I agree to having my anonymous quotations used in the reports for this study

☐

6. I agree to sections of my medical notes which are relevant to my taking part in this research being accessed by Sarah Mann, Trainee Clinical Psychologist.

☐

7. I understand that information will be stored confidentially according to the NHS code of ethics.

☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

Appendix 8: Example Research Memos

Memos: Paediatric disclosure and friendships

Memos from early stages of data collection (Interviews 1-3)

Paediatric disclosure has been described as a big shock by participants so far – this experience still seems very ‘raw’ to participants. What is the effect of paediatric disclosure and this experience of shock/fear/confusion on the participants’ friendships then and/or now?

-Option 1: Maybe paediatric disclosure actually has no effect at all on friendships at the time – if it is such a difficult piece of information to hear and understand, then participants might have felt there was no chance at all of them sharing it with friends. Perhaps they just carried on in the same way they always had? As if that had never happened? Because the possibility/likelihood of discussing or sharing their status with someone was so remote or too overwhelming to comprehend. Examples:

- *“But er, umm... My friendships, you know, they stayed the same, because, yeah I think I was at the age I just didn’t understand what it was”* (participant 1)
- *“I didn’t really know anything about it. I thought I was going to die. When I was actually diagnosed with it I thought that that meant I was going to die”* (participant 2)

-Option 2: Maybe paediatric disclosure has a huge effect on friendships, the decision taken at that time not to share their HIV status is the first step on a path to secrecy and concealing this information from friends. Examples:

- *“I just kept that to myself. I didn’t tell anybody. ‘Cause for that moment you feel like you’re different compared to the whole world”* (participant 3)

How does this change the participants’ sense of who they are as a friend? They have just learned that they are someone who’s identity includes being HIV-positive (which was a shock/upsetting) and maybe they are also dealing with a change in their identity around ‘being a friend’ too. Now they are a friend who keeps one part of themselves hidden / a secret from their peers – how does this feel to them?

How does it fit with their view of what a friend should be? -> examine data emerging from interview questions about the qualities valued in friendships – if participants value honesty / openness / trust etc. then how does this relate to how they end up feeling about hiding their HIV status?

-Option 3: If, in later interviews, some participants do report sharing their status at the time of paediatric disclosure, then how do their friends react? Especially given the age of participants and friends at that time – how likely are friends to be able to respond supportively? Or even to understand what they have been told? How would

this leave the participants feeling – they are already feeling confused and overwhelmed, having a friend who did not understand HIV either could be detrimental to their wellbeing.

Initial codes:

Not understanding HIV status at time of paediatric disclosure

Believing that I would die from HIV at time of disclosure

Not knowing what to say upon learning of HIV status so deciding to say nothing

Deciding not to disclose to anyone at school

Memos from mid stages of data collection (Interviews 4 – 6)

All participants so far continue to report paediatric disclosure as being a shock and causing them to feel afraid / scared / overwhelmed. No participants have reported sharing their status with friends at time of paediatric disclosure, so option 3 (above) seems unlikely to end up being part of young peoples' experiences.

More data is emerging for option 2 (above). The interviews with participants 5 and 6 highlighted another aspect to not understating HIV at the time of paediatric disclosure – that their experience of living with PAH did not match what they thought / knew about how unwell people can get when they have HIV. Examples:

“Ummm I didn’t really think of telling anyone at that time” (participant 4)

“I thought people living with HIV always get sick, you know? I’d never been sick” (participant 5)

Both of these participants were born in sub-Saharan Africa -> how might their experience of seeing people living with HIV be different than someone who was born in the UK? What is the general level of knowledge about PAH in the world?

Participant 4 referred to paediatric disclosure happening at a significant time of transition in their life, as it happened when they were moving schools. Participant 2 also referred to this. So *timing* of paediatric disclosure might also be relevant to its effects on friendships of young people living with PAH. WHO guidelines advise paediatric disclosure by age 12 – if this is being adhered to and is true for all participants, then maybe young people with PAH always have to contend with moving schools and losing/making new friends at the same time they learn their HIV status? Which will also surely have an effect on how able they feel to share their status – are they close enough to these friends? Do they have enough to deal with already around that transition without thinking about disclosure decisions too? This

seems like one example of the interplay between the tasks of adolescence and living with PAH. Example:

“Especially because I was like just going to secondary school. So like a lot of the people I was with at secondary school, like I didn’t really know them that well So I didn’t really think of telling them” (participant 4)

Initial codes:

The impact of discovering HIV status at a time of change in your life (moving schools)
Understanding about routes of HIV transmission

Memos from final stages of data collection (Interviews 7 – 9)

These interviews have presented more data on how scared participants were at time of paediatric disclosure. No participant at all has reported sharing their status with friends at the time of paediatric disclosure. The shock and lack of understanding seem very influential in that decision, as all participants have referred to those experiences – none have said, for example, that they news was received calmly / went well / was not a surprise. For example:

“it just sounds like you know like a history lesson where you hear loads of facts but it doesn’t.... mean anything ... ‘cause all you hear about, all you... All I believed was what I heard about how many young people die from it”
(participant 7)

Participant 8 is the only person who has no reported paediatric disclosure to be influential in their disclosure decision – they were told the most recently though and were amongst the oldest at the time of paediatric disclosure, so I wonder if they had raised discussed their suspicions with friends beforehand? It hasn’t come up in any of these interviews but that could be another aspect of friendships and PAH – do any young people living with PAH discuss their suspicions with friends about what their diagnosis might be? Probably not given HIV-stigma.

In total, only two participants in the study have gone on to actually actively share their HIV status with friends – others have either never told their friends, or have only done so in ‘part-disclosure’, unplanned disclosure a one off, or had a friends guess their status. So, the experience of paediatric disclosure could actually be central to the friendship experiences of young people living with PAH – it does seem to have been the start of a trajectory of concealing HIV status within friendships for the majority of participants.

Participants 5, 7 and 9 were all older at the time of paediatric disclosure – and they still did not share their status with anyone that time. So maybe the decision not to share status following paediatric disclosure isn’t entirely due to changing schools or

it being a transitional time, maybe it is more explained by the lack of understanding/feeling overwhelmed/ feeling afraid.

Other links to consider:

-> Links to mother's advice about disclosure / HIV secrecy at home?

-> Links to wider context of HIV stigma / attitudes?

Possible theoretical code:

Effect / Influence / Role of paediatric disclosure on friendships

Memo: Sharing HIV status with friends

Memos from the final stages of data collection

The final two participants have been able to share their HIV status with several friends. A combination of: feeling able to share their status and going on to carry out the act of sharing their status differentiates them from the other 7 participants. Other participants have expressed wanting to share their status and also planning how they would do so, but have not gone through with this. Have they encountered other barriers or had other negative experiences that these two participants had not? Two participants had, in the context of partners reacting 'badly' to them sharing their status. This previous experience is likely to be influential to whether they want to share their status with friends (reinforcing non-disclosure). Other participants do not seem to vastly differ from participants 8 and 9 though. In fact, participants have had quite similar experiences in other aspects of living with HIV – all being shocked at paediatric disclosure, all thinking a lot about disclosure decisions etc. So in one sense these participants have confirmed that a lot of the influences on disclosure decision may be the same throughout the PAH population. But how did these two participants go on to end up in a position that so many others had not? Maybe it is to do with the friend e.g. as highlighted in some of the current emerging codes relating to establishing a friend's reaction in advance or feeling certain that particular friends will react well. Participant 9 had done this in a more detailed way than other participants had – she actively asked friends 'difficult' questions to get a good sense of their values and ideas. Perhaps she therefore felt more confident that the reaction to sharing her status would not be an upsetting one. Participant 8 described trusting that his friends would not joke with the information about his HIV status or disrespect it, therefore he felt safe and able to share this information. Other participants also referred to believing their friends would react well to them sharing their status, but still viewed this as too big of a chance or too big of a risk to take. So perhaps some degree of certainty about how their friends will react is being revealed by these final two participants? Or maybe they perceive the risks around

disclosure differently than previous participants have. Need to review the codes to see which are most prominent in the experience of participants who had and had not shared their status. The disclosure decision is certainly appearing to be a central influence on the friendship experiences of young people living with PAH.

Contrasting experiences for example:

- *"It's so hard to just, you know, go out there and tell someone... Oh my god, I can't even imagine myself doing it, like, go out there and tell someone?! It's really hard"* (participant 6)

AND

- *"Yeah when everyone's talking about health stuff then it's easy to drop it in there
And then just move on, yeah"* (participant 8)

Other links to consider

->how does disclosure decision relate to whether participant believes their friend should or needs to know their HIV status? 'Just no need for them to know' has been reported by several participants – so need to consider whether it is fear and anticipated stigma which are barriers to disclosure or the participants own beliefs about HIV? And their ability to cope with it? For example:

- *"You know it's just the whole trust thing, and I do trust my best friend, but at the same time it's like... I just don't feel she needs to know"* (participant 3)

Appendix 9: Extracts from Researcher's Reflective Diary

No participant so far has reported being able to share their HIV status with their friends. I assumed when embarking on this study that most participants would have shared their HIV status with friends and would be accessing support from them where needed. I have clearly underestimated the levels of HIV stigma which are still present today. This is somewhat of a surprise to me as I generally perceive myself to be someone who is 'in tune' with the experiences of other people and the wider context I live in. Maybe because I have travelled in sub-Saharan Africa where people living with HIV face significant challenges and stigma, I reached an assumption that living with HIV in London would be very different (and easier?) –no doubt it is in many ways – but the levels of HIV stigma appears to remain higher than I had anticipated. My day to day life does not affiliate me with any minority groups– I am a heterosexual white British female, with no chronic health condition, physical or intellectual disability. So perhaps I am naïve to the levels of difficulty faced by many of these populations as I have never faced equivalent worries or challenges.

The participants who have been most upset so far about not being able to share their HIV status with friends have been male. This has caused me to think about my own assumptions around gender and accessing emotional support. I found myself assuming that these male participants were expressing more emotion in the room, because they did not have other avenues to do so. I wondered whether young female participants will report sharing their HIV status with more friends? Have they been more able to express their difficulties or more likely to perceive this as an acceptable thing to do based on their own gender related beliefs? ,I wonder whether the male participants would have responded differently to a male researcher – would they have felt they needed 'put on a brave face' in the same way they had been for many years already?

I have been thinking about how the participants who have not shared their HIV status with anyone, might be experiencing participation. This is mainly based on the realisation that I am now one more person amongst only a handful of people who know their HIV status. Maybe participants had not thought much of this, if they viewed me more as part of the medical team at the clinic who knew their HIV status. Other participants have noted however, how strange it feels to them even saying 'HIV-positive' out loud, as if they had not shared their status with anyone they never really say this. Despite clear confidentiality boundaries, about the information, it may still have felt uncomfortable for participants in the room/our interaction/conversation to meet a new person and thus reveal their HIV status to a stranger, when they usually go to such great lengths to conceal this information from everybody they meet.

Appendix 10: Sample Transcript Extract and Coding

Transcript	Initial Code	Focused Code
<p>P: Yeah, I think it's just that the extra thoughts to it</p> <p>like all my other friends that don't know it's like should I tell them?</p> <p>Do I feel comfortable telling them, like,</p> <p>it would make life easier</p> <p>but is it the right time, kind of thing</p> <p>'cause I've always got those thoughts in the back of my mind when I'm having conversations with people</p> <p><i>I: It's there kind of all the time, when you are talking to people?</i></p> <p>P: Yeah all the time, like any friend</p>	<p>Reflecting on complexity of HIV disclosure in friendships</p> <p>Playing out possible disclosure scenarios in my mind Having both types of friend – those who do and do not know HIV status</p> <p>Identifying conditions necessary for sharing status with friends Protecting self against distress by not sharing HIV status</p> <p>Anticipating what the benefits of sharing HIV status might be</p> <p>Expressing ambivalence about disclosure. Wanting to share HIV status but feeling unable to</p> <p>Thinking about disclosure</p> <p>Thinking a lot about whether or not to share HIV status Disclosure decision affecting interactions with friends</p>	<p>Thinking about disclosure process in advance</p> <p>Thinking about disclosure process in advance</p>

<p><i>I: Right</i></p> <p>P: And it's like, I think the more people you tell the more comfortable you get</p> <p>And it's like should I tell them just for the sake of it? Just so they know, kind of thing</p> <p><i>I: Yeah</i></p> <p>P: But then there is always that feeling of like well they might react negatively,</p> <p>I don't know them enough,</p> <p>that kind of thing</p> <p><i>I: Yeah</i></p> <p>P: Yeah, so it's definitely one thing that does definitely bug me</p> <p><i>I: That's something you think about?</i></p> <p>P: Yeah</p>	<p>Feeling confident to make subsequent disclosures after sharing HIV status</p> <p>Wanting to share HIV status Finding reason to / not to share HIV status with friends</p> <p>Wanting to share status with friends but viewing it as too risky</p> <p>Feeling afraid of sharing status. Feeling scared friends would react badly</p> <p>Finding reason not to share HIV status with friends Expressing perceived barriers to sharing HIV status</p> <p>Feeling annoyed about wanting to share HIV status but feeling unable to.</p> <p>Thinking about disclosure.</p>	<p>Recognising the positive effects of sharing HIV status</p> <p>Anticipating stigma in response to HIV status</p> <p>Thinking about disclosure process in advance</p>
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<p><i>I: And just, just to clarify so I can understand - when you're saying they may react negatively...</i></p> <p>P: Yeah</p> <p><i>I: What sort of things come to your mind?</i></p> <p>P: Like, erm... leaving me as a friend I guess</p> <p><i>I: Uh huh</i></p> <p>P: Telling others,</p> <p>like so I also have to think about what would I do with out them kind of thing, would I like miss them?</p> <p>(laughs) like, yeah it's kind of sad, but yeah</p>	<p>Feeling scared that friends would leave if they knew HIV status</p> <p>Feeling afraid of people making indirect disclosures</p> <p>Thinking about how friends might react</p> <p>Wondering how to cope if friends left me.</p> <p>Imagining negative reaction to disclosure, feeling sad (?or dismissing significance of?) when thinking about possible reactions to disclosure</p>	<p>Anticipating stigma in response to HIV status</p> <p>Experiencing distress around disclosure decision</p>
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Appendix 11: Table Illustrating how the Data from Each Interview Contributed to Codes During Analysis

Theoretical Code	Focussed Codes	PP1	PP2	PP3	PP4	PP5	PP6	PP7	PP8	PP9
1. Influence of Paediatric disclosure experience on current friendships	1.1 Perceptions of HIV at time of paediatric disclosure	X	X	X	X	X	X	X		X
	1.2 Feeling unable to share status with anyone following paediatric disclosure	X	X	X	X	X	X			X
2. Influence of Mother's HIV status on current friendship decisions	2.1 Influence of Mother being HIV-positive on sharing own status	X			X			X	X	X
	2.2 Role of mother in managing HIV status	X	X	X	X			X	X	X
3. Deciding whether or not to disclose status to friends	3.1. Beliefs about needing support from friends to manage HIV			X		X	X		X	
	3.2 Thinking about the disclosure process in advance	X	X	X	X	X	X	X	X	X
	3.3 Anticipating discrimination in response to HIV status	X	X	X						X
	3.4 Establishing friend's possible reaction to disclosure			X	X	X		X	X	X
	3.5 Experiencing distress around disclosure decision	X	X	X	X	X	X	X		X
4. Friendships with other people who do know HIV status	4.1 Disclosing to friends increases support			X				X	X	X
	4.2 Support for managing HIV in intimate relationships			X				X	X	
	4.3 Recognising positive effects of disclosure		X		X			X		X

Theoretical Code	Focussed Codes	PP1	PP2	PP3	PP4	PP5	PP6	PP7	PP8	PP9
	4.4 Feeling surprised by reaction to disclosure		X	X				X	X	X
	4.4 Having to educate friends about HIV post disclosure							X	X	X
5. Friendships with other people who don't know HIV status	5.1 Receiving Support from friends even if they don't know status	X	X	X	X		X			
	5.2 Implementing Strategies to keep HIV status a secret	X	X	X		X				
	5.3 Friendships and HIV in the future	X	X		X	X	X	X	X	X
6. Friendships with other young people living with PAH	6.1 Differences between friendships with PAH youth and other friendships		X		X		X			X
	6.2 Valuing shared experience of being friends with other young people who have PAH		X	X			X			X
	6.3 Not wanting to make friends with other PAH youth at support groups	X	X	X				X		
7. Defining different friendships	7.1 Identifying different categories of friendships		X	X	X		X		X	X
	7.2 Trust and friendships	X			X				X	X
8. Attitudes towards HIV	8.1 Personal attitude to privacy of HIV status	X		X	X			X		X
	8.2 Personal adjustment to HIV				X	X	X		X	

<u>Theoretical Code</u>	<u>Focussed Codes</u>	<u>PP1</u>	<u>PP2</u>	<u>PP3</u>	<u>PP4</u>	<u>PP5</u>	<u>PP6</u>	<u>PP7</u>	<u>PP8</u>	<u>PP9</u>
	8.3 Considering wider context of people's beliefs about HIV transmission in relation to PAH	X		X		X	X	X	X	X